

# Planning and talking to help minimise distress associated with death, dying and bereavement: The role of public health

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## **Abstract**

### **Background**

People who are dying, caring for somebody who is dying, or have been bereaved can experience problems such as isolation, depression and anxiety. Some of these problems might be reduced if people were better prepared for death and were able to support one another when they were affected by death. There has been little previous research into how public health interventions might encourage these changes at a population level. This thesis aimed to explore this subject with a particular focus on talking to family and friends about end of life preparations and preferences. The research was embedded within the new and innovative Cheshire Living Well Dying Well (CLWDW) public health programme, which was established to address the issues described.

### **Methods**

Mixed methods were used. A quantitative follow-up survey was used to test a CLWDW intervention to encourage people to prepare for the end of their life and to discuss their end of life preferences with the people closest to them. A qualitative interview study was used to explore the wider context in which people talk with one another about issues relating to death and dying.

### **Findings**

The CLWDW interactive presentations delivered to community groups and to people working in health and social care were well received and effective in encouraging appropriate actions. Of respondents who completed follow-up at three months post-event (28% response rate), 60% reported that they had made a change or taken some action as a result of the event, including 43% who had talked with somebody about their own end of life wishes. In interviews, participants of all ages expressed the view that death, particularly bereavement, was a crucial issue and that it was important to prepare for and to talk about death and bereavement. Various barriers to talking about, preparing for and supporting people affected by death were described, as were various ideas to support improvement.

### **Conclusions**

Most people in the UK consider it important to be prepared for end of life and death, although many have not made these preparations. In the right circumstances, most are willing and able to talk openly about death and dying, including their own end of life preferences. Appropriate population-level interventions to encourage these behaviours can be well received and effective.

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# **1. Introduction**

## **1.1 Death as a public health issue**

This thesis considers health and social problems associated with death, dying and bereavement as a public health issue, according to the World Health Organization (WHO) definition of health as ‘...a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ [1]. Public Health is defined by the UK Faculty of Public Health as ‘The science and art of promoting and protecting health and well-being, preventing ill-health and prolonging life through the organised efforts of society’ [2]. Public health has traditionally focussed on preventing premature death; however, it is increasingly recognised that dying and bereavement can be associated with significant avoidable ill-health, which might be reduced through appropriate population-level (public health) intervention [3].

There are two different models of public health as it relates to death, dying and bereavement:

- The health service provision model. This focuses on providing adequate and appropriate palliative healthcare services according to the assessed needs of the population [4].
- The ‘new public health model’. This focuses on public education and community capacity building, where the community are involved in setting priorities. It aims to empower people to better support each other and improve their own health and wellbeing [5].

The two models are complementary. While formal healthcare is important and necessary, it is limited in the scope of support it can provide, and would be prohibitively expensive if it tried to fulfil all needs. In contrast, community capacity building can have a wider reach, be more flexible and far less expensive than formal healthcare. Public health, as referred to in this thesis relates to the ‘new public health’ model, as the former is more researched and established.

## **1.2 How death impacts on population health**

In England and Wales, the death rate is currently around 1% [6] per year, and is expected to rise, despite increasing life expectancy, due to an aging population structure [4]. It has been estimated that each death directly affects an average of five people through caring and grieving [4]. In a recent random population survey,

54% of adults in England and Wales reported that they had experienced the death of somebody close to them in the previous five years [7]. In a recent survey, the majority of people in England [8] reported that had attended a funeral in their lifetime: 75% at age 16-24, 97% at age 35 to 44 and 100% at age 65 to 74.

Dying is not always associated with pain and suffering, although people who are ill and close to death may suffer with physical symptoms, depression or anxiety [9]. They may have worries about how or where they will die [10], including worries about becoming a burden to others [10]. They may go through a kind of bereavement process themselves as they suffer loss of health, strength and role [11]. Some people have a fearful reluctance to die [12]. Informal carers of people who are dying may also suffer ill-health. In a study of 893 family caregivers for people with a terminal illness in the USA, 31.4% of carers of those with a substantial care need reported symptoms of depression, and similar proportions reported that that caring was interfering with family or personal life [13].

Bereavement is distressing for most people who experience it, often involving not only significant loss but transition to a new role [14]. The associated grief process varies greatly from person to person and, in some cases, may never be fully resolved [15]. Grief may also be felt before a death, where a loved one is incapacitated or dying, in the form of anticipatory grief or grief for the loss of a person as they were. Symptoms of depression or anxiety are common [16], as are physical symptoms such as backache and fatigue. People who have been recently bereaved are also more vulnerable to physical illness, including cardiovascular diseases and cancer, and suffer increased mortality [17].

### **1.3 The role of public health and open discussion about death**

It is widely believed that there is a lack of openness in society about death, often described as a taboo, which adversely affects the wellbeing of those affected by death, dying and bereavement. This area is discussed further in the Background Chapter 2. There is a growing recognition, in the UK and beyond, that society's attitudes towards the discussions of death, dying and bereavement play an important role in the delivery of person-centred end of life care services, the availability of understanding and support for the bereaved, and the long-term health and wellbeing of individuals and communities [18]. In the 2013 review of the Liverpool Care Pathway for the Dying Patient [19], Baroness Neuberger concluded:

*“No matter how much effort is put into training clinicians in good communication skills, unless everyone in society – members of the public, the press, clinicians, public figures – is prepared to talk openly and honestly about dying, death and bereavement, accepting these as a normal part of life, the quality of care and the range of services for the dying, their relatives and carers will remain inconsistent.....”*

The theory behind the new public health approach to death and dying is that in modern society communities often do not know how to provide support to their own members. This can mean that those who are living with thoughts of their impending death, or who have been bereaved, may not get the help and support from friends, neighbours and loved ones that they need to cope with their situation. Living within a society that is uncomfortable talking about death and dying means that people may be unprepared for death, and health and social care professionals may find it difficult to engage in open and sensitive conversations with patients and carers.

Alan Kellehear, when introducing the concept of Health Promoting Palliative Care in 1999 [5] and Compassionate Cities in 2005 [20], argued that community care of people who were dying, caring for somebody who was dying or bereaved preceded professional care, and that community members still could and should have a significant role. Among the suggested methods to facilitate this were 'death education' to help communities prepare for death, and other activities to help to 'normalise' death as something that is part of life and can be talked about. Around the same time, a review conducted by Larson and Tobin in the USA highlighted the difficulties in discussing end of life medical care in case of advanced illness and recommended community awareness raising initiatives as part of the solution [21].

The concept of 'Compassionate Cities' was particularly influential. It was based on the WHO 'Healthy Cities' model [22], developed in 1986 and arising from the Ottawa Charter for Health Promotion developed in the same year [23]. A healthy city is still defined by WHO as “continually creating and improving those physical and social environments and expanding those community resources which enable people to mutually support each other in performing all the functions of life and developing to their maximum potential”. Alan Kellehear's central argument was that that dying, death and bereavement should not be excluded from this model of mutual support, which could apply both to cities and to other types of community comprising of towns and villages. The original concept of 'Compassionate Cities' is now more

often referred to as 'Compassionate Communities' [24] to reflect its applicability to all geographic areas.

A conceptual framework very similar to Compassionate Communities seems to have been developed separately in the USA, described by Byock et al in 2001 [25] as a 'whole community approach to end of life experience', including terminal illness, sudden death, family caregiving, and grieving. The authors suggested that the highest quality of life would be achieved community-wide when dying, caregiving and grieving are recognised as aspects of life, and that this would require a cultural shift. The suggested that the indicators of this shift would be:

- An adult population composed of individuals who have prepared for dying through discussions with family, friends, neighbours and healthcare and other professionals
- A population in which people support, and feel supported by, one another during times of caregiving and grief.
- Schools, faith communities, businesses, associations, and social clubs that commonly include issues and activities pertinent to dying, caregiving and bereavement in their agendas.

Byock et al suggested a social marketing and community development approach that would include organising and supporting groups of community members to use research to develop, implement and test interventions.

These ideas are now being incorporated into public policy. In 2005, The International Work Group on Death, Dying and Bereavement [26] recommended a combined approach from Public Health and End of Life Care providers to the normalisation of death, dying and loss within society at large. In 2008, the Department of Health in England published its first End of Life Care Strategy [27], the main focus of which was identifying people in their last year of life and initiating discussions about end of life care. It included a chapter on societal lack of openness about death and dying, perceived as causing unnecessary suffering through limiting communication about future wishes and preferences with loved ones. In response to this, the National Council for Palliative Care [28], an umbrella charity for all those involved in palliative, end of life and hospice care, set up the Dying Matters Coalition (<http://www.dyingmatters.org>) to "Support changing knowledge, attitudes and behaviours towards dying, death and bereavement and through this making 'living and dying well' the norm.



Also in 2008, the Scottish government published its end of life care strategy, “Living and Dying Well” [29]. This recommended the establishment of a number of short life working groups to take forward further development work on specific issues. Short Life Working Group 7 was set up to explore ideas for facilitating wider discussions of death, dying and bereavement across society [18]. This group set out a vision for what a good society would look like:

- People are able to talk about death and deal with related issues in a constructive way
- Children grow up treating death as an inevitable part of ordinary life
- People are comfortable using words such as ‘death’, ‘dead’ and ‘dying’ and are able to make choices relating to their own dying and death
- Health and social care professionals and volunteers in all care settings feel able to have discussion relating to death, dying and bereavement with patients and families, and with colleagues
- Communities of all kinds are empowered to provide effective support to those dealing with death, dying, bereavement and loss

This vision provides a useful summary of the intended positive effects of public health strategies designed to help normalise talking about and planning for dying and death.

## **1.4 Aims and context of this thesis**

Although the normalisation of death, including encouragement of open and positive communication about end of life wishes with loved ones, is now recognised as a public health priority, there is very little research evidence as to what interventions would be effective in facilitating this (see Literature Review Chapter 3). Indeed, there is little research into the impact that these conversations can have on individuals and the wider community. This has not prevented various projects being initiated, based on general principles of health promotion [24]. However, if this type of work is to continue, grow in effectiveness, and attract funding, it is important to develop an evidence base that is specific to the subject.

This thesis was supported by and embedded within the Cheshire Living Well Dying Well (CLWDW) public health programme; based at St Luke’s (Cheshire) Hospice in Winsford, Cheshire (described in greater detail in the Background chapter). As part

of its overall strategy to change public attitudes, CLWDW has delivered a number of innovative public health interventions designed to encourage members of the public to consider and to talk more openly together about death, dying and loss. This thesis examines the impact of two of those interventions and also looks at the views and priorities of the general public regarding planning for end of life and talking about death, dying and bereavement. In this way it aims to add to this evidence base, both of which health activities can encourage planning for and discussion of issues relating to end of life and death; and considering the potential impacts of success. A further discussion of the research questions is presented in the Methodology Chapter 5

## **2. Background**

This section describes the background to the thesis in terms of the social history and current social experience of death, dying and bereavement; current attitudes to preparing for and talking about death and dying; and the work undertaken by the Cheshire Living Well Dying Well Programme. It is presented from a mainly 'western' perspective, which reflects both the area in which the research was conducted, and also the paucity of research from other cultures.

### **2.1 The social history of dying and bereavement**

According to Aries [30], in the middle ages people expected to be forewarned of their death; a sort of feeling in the body. Preparations were simple and involved mainly lying down and waiting. Priests delivered the last rites and many people would visit the dying person, including children. The dying person would be in charge of the process of their own death. People were familiar with dead bodies as they were dug up for reburial when space was needed. Beginning in the 18<sup>th</sup> century, people became less interested in their own death and more interested in the loss and memory of others. The ceremony of the death bed surrounded by family remained, but it was expected to be more emotional than it had been in the past [30].

From the 13<sup>th</sup> century to the 18<sup>th</sup> century, a will was not just a legal document, but expressed a person's deepest thoughts and wishes very personally. After the 18<sup>th</sup> century, any wishes other than financial wishes were expressed orally to the family. Mourning was expected to be more emotional. People became less willing to accept the departure of their loved ones and began to pay more attention to tombs and reminders of the physical location of death. Visiting a tomb full of memories was important, as memory conferred a sort of immortality [30].

During the middle of the 19<sup>th</sup> century, death started to be seen as something that was shameful [31], and people started to hide knowledge of imminent death from the dying person. Later the topic of death had to be avoided for the sake of society and those close to the dying one, to avoid the strong emotion caused by the death. Since the 1930s, death in developed countries has gradually moved from home to hospital or nursing home, and now often occurs alone [30, 31]. Emotional grief became less acceptable and mourning clothes were no longer worn. There was a

moral duty to contribute to collective happiness by not showing sadness. Cremation became more common, so there was often no graveside to visit [30].

In recent years, some of these trends have started to reverse. In the 1960s, research in hospitals showed that most people who were dying were aware of the fact [32], which created a situation of 'closed awareness', in which they were unable to help relatives in their grief or confront their own feelings about dying. This research led to changes in healthcare practice, whereby patients were informed of their prognosis, with a subsequent move towards aware dying. A new discourse of dying began; revivalism [33]. Revivalism includes the elevation of experiences of death and dying so they are brought into public discussion and consciousness. The dying person is constructed as the chief mourner in their own death and dying is transformed into an opportunity for personal growth and affirmation of the caring bonds [12].

Since 2004 there has also been a slight reversal of the trend away from home deaths in England and Wales, although in 2010 still only 20.8% of deaths occurred at home [34].

## **2.2 The social experience of dying**

In the UK and other developed (high income) countries, most people die in old age; in England between 2008 and 2010, 66.7% of people who died were over the age of 75 and 36.2% were over the age 85 [35]. In a large cohort study conducted in the USA, four main end of life decline trajectories were identified [36, 37]; sudden death (15%); short period of decline typical of cancer (21%); long-term limitations with intermittent serious episodes typical of organ failure (21%); and prolonged decline typical of frail elderly people and people with dementia (20%). The remaining 24% died following other, varied trajectories. In the UK at present, there is probably a greater proportion following the prolonged dwindling trajectory; in 2011, 17.3% of death certificates had dementia recorded as a contributor to death [35]. Life expectancy and average age at death is continuing to increase [4]. As this occurs, the proportion of people who experience frail old age and dementia is also expected to increase.

Different dying trajectories have different consequences for social participation [12, 38]. Some conditions, e.g. COPD and heart failure, may entail a long period of

'careful living' in which the possibility of death is a background presence, but not a certainty [12]. Alternatively, they may be unaware that the prognosis is probably eventually terminal [38, 39]. Where death is preceded by a period of illness, physical restrictions can lead to an inability to maintain social contacts or restriction of the form they take. Diseases of old age often cause disability of various sorts before death, merging the experiences of dying and old age [38]. In extreme old age, or in diseases where mind and body disintegrate, social death may precede biological death.

Much of the current discourse about dying refers to aware dying and to the cancer type dying trajectory in particular. Dying can be associated with suffering, described by Saunders and Baines [38] as 'total pain', having four dimensions: physical pain; social pain (distress about relationships); spiritual pain (feeling that suffering has no meaning or purpose) and mental pain (negative feelings about death and loss). Kubler-Ross [40] described the emotions associated with dying as a series of stages, similar to the stages of grief following bereavement [41], beginning with shock and denial at diagnosis followed by a period of depression and ending with a period of acceptance.

Death has also been conceptualised as a break to social bonds [12] which onlookers try to maintain by caring. Ageing and dying can be seen as a series of losses, e.g. loss of independence, loss of food, eventual loss of life. Help or surveillance by the neighbours might therefore be resisted, as it might be considered a mark of loss of independence and the start of social death.

In 1986, a qualitative survey was undertaken with 250 people in England who had known somebody who had died, and had known that they were dying, in the previous year [42, 43]. Respondents described how the person who was dying often wanted to get their affairs in order, distribute possessions, and give instructions for after their death. Relatives wanted to 'do as best as they could', let the person know that they cared for them, and be with them during the dying process. Ultimate acceptance of death was thought to give a sense of peace. However, some did not want to enter the dying role as they preferred to carry on as normal, and some relatives wanted to protect them from the knowledge that they were dying so as for them not to lose hope. The authors noted that this aware dying role was not available to those who were very elderly or had dementia. Even when the physical trajectory allowed aware dying, awareness was more likely in people of higher social class, who were also more likely to have a will or life insurance policy. Others have

also noted that, where dying is protracted, the process is less clear cut and 'aware dying' may not be possible. Lawton quotes an elderly patient as saying, "*Death keeps taking little bits of me*" [44]. Some very elderly people might even say that they have lived too long [45]. Therefore only a relatively small proportion of the population experience this aware dying process around which so much of the academic and policy discourse, including the revivalist movement, is based.

## **2.3 Views about dying**

As humans we are probably the only species aware of our own mortality, which can create fear and worries, although more people report fear of the dying process than of death itself [46]. In a national survey, 8% of UK adults said they were 'very' or 'extremely' afraid of dying, while 34% said they feared being in pain before they died 'very much' or 'extreme amount' [47]. Other research found that people fear helplessness and dependency in old age more than they fear death [48], while many worry more about how their families would cope with their death [49]. Death anxiety in people with a terminal illness has been described as having four components [50]; fear of the unknown; fear of loneliness at the time of death; fear of suffering; and fear of personal extinction. One study found that fear of death was associated with lower quality of life in people who are older or who have a life-limiting illness [50], although the direction of causality was unclear.

A recent systematic literature review revealed that people throughout the world share core ideals of a 'good death' [51], which include being free of pain and other symptoms, being with friends and family, not being a burden, being listened to, being able to decide about medical treatments [52] and being treated with respect. In some studies 'having one's affairs in order' was highlighted as important, while religion or spirituality was important to some people [53-55]. Many people would like to be cared for at home during their final illness [56-58]. Some ideals are specific to certain cultures, for example, in Japan many people express a preference for being unaware of their forthcoming death [59]; and spiritual and religious issues are less important than in the USA.

In a 1990s qualitative study of maintenance of independence in older people over the age of 75 who lived in their own home in North London, 42 of 72 participants (58%) made some mention of death [60]. The more able bodied and socially active respondents generally had little time for thoughts of death and preferred to

concentrate on living. Participants generally wanted a quick death, but they also wanted some warning so that they could say goodbye to friends and family and ensure that their affairs were in order. Death might be viewed as time to step aside and make way for younger generations, and having seen children and grandchildren grow to maturity were seen as a completion of life-goals. Others believed in the after-life and a prospect of being reunited with people who had gone before. Many put aside money for their funeral to ensure that they would not be a burden on their family. Some deprived themselves of luxuries to do this, and also told their relatives of special requests for their funeral, such as a piece of music.

Although there has been less research on the subject, there is also evidence that people have strong feelings and hopes for how their loved ones will die. When the sociologist Lawton spoke publicly on her work on the dying process, she described how she had often been approached by people who felt a sense of failure because their relative had not died in the way he or she had expected or hoped for [44].

## **2.4 Experience of bereavement and grief**

Grief usually occurs with the loss of an emotional partner, child, or a parent to whom one was close. It can also occur where a person loses all of one type of relationship in a community, for example with the loss of employment [61]. Grief and recovery follow different courses for different people and grieving often takes considerable time; for example, most widows are still grieving 13 months after the deaths of their husbands [62]. Some people never fully resolve their grief [15]. People are generally less distressed at the death of an elderly person than of a young person [11]. However, losing a spouse in old age can be traumatic, and some report that they felt they had lost a part of themselves [60]. A sudden death might be more initially traumatic than a death that is expected [63], and people who have other disadvantages such as concurrent crises, reduced material resources or poor health might suffer particularly debilitation grief [63]. The loss of a child is particularly difficult and in this case grief may last many years [61, 64].

Physical and mental health can be affected; in a study of 350 widows and widowers, compared with married control of the same age, the recently bereaved were significantly more likely to report poor health, symptoms of depression or anxiety, and increased use of cigarettes and alcohol [15]. The symptoms of grief following a

bereavement can occasionally be so persistent and distressing that a person can be diagnosed with a condition known as 'complicated grief' or 'traumatic grief' [65, 66].

Many investigators have conceptualized the process of grief after bereavement as a series of stages, similar to those of a dying person [67], beginning with an initial period of shock and finishing with an acceptance of the loss and ability to move on with life without the person [15, 41, 68]. A more recent model [69] suggests it is more like a roller-coaster with gradual changes over time, and that people might want to retain memories of the deceased, rather than letting them go. It suggests that finding a secure place for the dead in one's mind may be aided by communal sharing of memories. In support of this model, in a study of elderly people who had lost a spouse, many reported continued communication with their late spouses.

Grieving at first comes in surges or pangs [70], then later surges occur at reminders of the loss that have not yet been dealt with. Contact with other people may cause these surges, yet is also helpful because of the role others can play in defining a loss and drawing a person into activities other than grieving [70]. Social support, even brief interactions where the loss is talked about, may help the bereaved to create, organise, or invest more fully in a personal story, which helps them to feel better. In a longitudinal study of bereaved spouses in the USA [71], a larger social network, which provided participants with more opportunities to express themselves, was associated with lower self-reported depression and more positive rating of coping, health and life satisfaction.

Bereavement usually affects more than one person and an entire group can be drawn into distress [72]. Because of their own grief, networks of friends or family members may sometimes be unable to support the person for whom the loss is most profound and immediate [73]. Within a family, bereavement may bring greater intimacy through sharing grief, or alternatively may exacerbate ongoing conflict [15].

The community might isolate the bereaved because people fear saying or doing the wrong thing; do not understand what has happened; or lack an appropriate ritual or etiquette to deal with them [70]. Another's loss may remind them of their own vulnerability or the neediness of a bereaved person might be burdensome to deal with. People also might draw away because they believe their distance is polite and respectful; because they think it is helpful not to acknowledge the loss; or are aware that well-meaning help can be a burden. Bereavement might also affect a person's ability to maintain social relationships, and they might isolate themselves. Even when they do not stay away, the 'support' of family and friends is not always helpful;



in a qualitative study in the USA, bereaved spouses reported disappointment, frustrations, anger and sadness because family and friends were judgemental, avoidance, inconsiderate, pushy or demanding [74].

Friends can be a major source of support for the bereaved, where they are able to provide empathy and sympathy, and accept fluctuations in mood and needs. Support might be practical (providing help with tasks); social (support to maintain social life) or emotional [67]. Those who have been similarly bereaved are often the greatest source of support. However, some people do not want to 'inflict' their grief on friends, and friends might struggle to cope with intense grief. Health care professionals may also be a source of support; but this depends on their communication skills, life experience and time available. Volunteers may often be a better source; they are seen as less threatening because they are not 'experts' and they have more time to listen [67].

## **2.5 Experience of caring for somebody who is ill and dying**

People who are caring for relatives and friends who are dying often experience practical and emotional burdens associated with caring [13]; and at the same time can experience anticipatory grief [75]. The restrictions placed on their lives by the burden of caring can be experienced as a form of 'social death' [76]. Those with the greatest caring burden tend to suffer the most. In large quantitative study of people with terminal illness and their caregivers in the USA [13], carers of people with substantial care needs, compared with those with fewer needs, were more likely to report depressive symptoms (31.4% compared with 24.8%) and that their role was interfering with personal or family life (35.6% compared with 24.3%,  $p=0.001$ ). The authors suggested that assistance such as transportation, homemaking and personal care could provide relief to the caregiver, helping them to maintain their own wellbeing and freeing them to offer more emotional and other support to the patient.

In another large study conducted in the UK, carers who were not the spouse of the person who was dying, for example, adult children and other relatives, experienced caring as more restrictive and burdensome than carers who were spouses [45]; however, carers could also experience caring for a dying person as rewarding, or equally balanced between rewarding and burdensome.

## **2.6 Theory of the ‘denial’ of death and ‘taboo’ around talking about death**

It is commonly accepted that death is often avoided as a topic of conversation. However, the reasons behind this are not agreed. The idea of the ‘death-denying’ society, known as the ‘denial of death thesis’, was first put forward in psychological and medical literature between 1955 and 1985 [77], and remains a popular idea, supported by the media. It refers to a taboo, which is said to involve a deeply rooted societal denial of death. The apparent evidence for this was that death was becoming ‘medicalized’, often occurring in hospitals away from other people (‘sequestered dying’ [78]), and that conversation about death was avoided and therefore ‘taboo’. It was thought to stem from the great medical advances that were made after the second world war, which created unrealistic optimism and a ‘conspiracy of silence’ where the medical staff knew the truth but withheld it from the patient. Some authors took the theory further by drawing parallels with pornography, suggesting that while death is unmentionable in polite society, this encourages violent literature and media portrayals of death [79] or described a furtive taboo against discussion of death and dying similar to the taboo on discussions about sex in Victorian times [80].

As far back as 1967, this ‘denial’ was described as a potential problem for health and wellbeing. Hinton [11] argued that attempts to ‘deny’ death are not wholly successful and when they fail people are ill-prepared for death when it comes and suffer because of this. People may accept death in the abstract but not consider their own deaths or the deaths of those they love except as something distant. Reluctance to face death means that people may be less inclined to get involved in the personal problems of the dying, so they suffer more [11].

More recently, Zimmerman and Rodi [77], Seale [12] and Kellehear [81] have argued against the ‘denial of death thesis’. They argue that society, rather than denying death, is actually organised to reduce the disruption caused by death [12, 81]; for example, medicine is employed to prevent untimely death, and life insurance and welfare states are employed to ameliorate the impact of death. The ‘communal’ dying of the past has probably been romanticised [12]. Segregation of the dying from the rest of society is not due to the desire to hide it away [77], but due to medical advances and changes to social structures that have occurred over the past century.

Kellehear argues that, while discussion of death is often avoided, this does not stem from death denial or taboo but aspirations for smooth relations and conduct [81]. He points out that because death is upsetting, it is 'sound interpersonal practice' to avoid it as a subject of conversation, and that, while this practice encourages denial, it does not stem from it. He suggests that to expect people to speak of death as easily as about any other subject is unrealistic and undesirable. Others have suggested that western worldviews are driven by individual success that is not so much death denying as death blind [82]. The idea of a taboo may stem from research conducted in hospitals, and might not apply to other settings. An essay by a medical oncologist in Toronto in 2008 suggested that discussions about dying may be made difficult by the euphemisms that are often used by healthcare staff instead of the word 'death' or 'die', which reduces clarity for the patient [83]. Some observers have suggested that, while death was previously taboo subject, that might no longer be the case. In a paper from the UK, published in 2002, Kafetz stated [84]: "*Death, previously a taboo subject, is now a topic of ordinary conversation*", and referenced the showing of the process of death on British television.

Seale [12] also suggests that the sociological concept of denial may have been conflated with the psychological concept of denial, which, although it has negative connotations, can be positive. In this case, preoccupation with death would result in loss of meaning in life and leading to depression. People therefore have a natural orientation towards life and symbolic immortality; the desire to be remembered after death, and to remember the dead. This healthy psychological denial does not correspond to a societal denial.

Zimmerman and Rodin [77] argue that there is not a need to change society's 'attitude' to dying but changing material condition that the dying and those caring for them have to face. For example, lack of financial support for lay caregivers.

## **2.7 Potential benefits of preparing for and talking openly about death**

'Having one's affairs in order', a common component of the idea of a 'good death' requires preparation, which might also assist people to have other end of life wishes met. However, there is limited research evidence on the effects of talking about end

of life preferences, and that which is available has focussed mainly on discussions in clinical settings between people with a life-limiting illness and their health care providers regarding end of life treatment and care. Much of this evidence comes from the USA where there has been a successful push towards advance care planning as a way of improving end of life care [85].

Research from the USA showed that people who discussed and recorded their preferences in the form of an Advance Directive (a legally-binding document of a person's preferences for medical care in event that they become incapacitated) were more likely to receive end of life care in accordance with their wishes [86-88] than those who had not, and this benefit was greatest if they had also discussed their wishes with somebody [89]. Where people had given power of attorney to relatives, relatives found it easier to make decisions if they had discussed the person's wishes in advance [90]. A cohort study of people with advanced cancer found that those who discussed their end of life care preferences with their doctors suffered less in their last week of life and their relatives suffered less depression six months later [91]. A trial in Australia [92], testing an intervention to facilitate advance care planning in elderly hospital inpatients, found the intervention improved end of life care and reduced stress, anxiety and depression in surviving relatives. A recently-published study from the USA showed that people who discussed their end of life care preferences with their next of kin had a higher probability of receiving hospice care at the end of their life than those who had not undertaken any advanced care planning [93]. In the USA, people who made their end of life care wishes known also had lower medical costs in the last week of life, mainly due to more limited use of intensive interventions [94]. This was probably influenced by the 'technical imperative' [95] in medicine; which is the pressure to do something, even if it would not be of benefit, if wishes are unknown.

However, if end of life care wishes are to be met, appropriate resources need to be available. A systematic review concluded that people with terminal cancer who expressed a preference to die at home were more likely to die at home than those who had not expressed a preference, but that other factors, including as having a supportive caregiver and sufficient community care resources were also important [96]. A study conducted in Japan showed that even if people expressed a preference for dying at home, if their relatives did not support it, it rarely happened [97].

As people get older, or their illness progresses, they often change their preferences relating to willingness to undergoing high burden treatments for a chance to postpone death [98, 99], suggesting that ongoing discussions are needed. People with newly diagnosed life-threatening or life-limiting illness often find it difficult to talk about their end of life preferences at this time [21]. People with serious illness may be preoccupied with day to day living and survival [100-102]; avoid thinking about death in order to better enjoy the present [49], or feel too unwell to think about making plans [103]. In the minds of patients and families, end of life decisions are often linked with the stopping of active treatment and the close proximity of death. However, patients often expect greater prognostic certainty than is possible. In modern healthcare, illnesses are becoming less often designated as terminal [104] and cessation of active treatment often occurs too late for effective end of life care planning to happen [105]. People who die or become incapacitated suddenly may miss the opportunity to discuss their end of life preferences. This suggests probable benefits in discussing end of life preferences while well, before death seems close, and before sudden death or incapacity makes it too late.

There is evidence that talking with somebody who is dying, about the fact that they are dying, can help to avoid regrets. In a 1990s qualitative interview study of older people in London [60], one participant regretted not sharing an awareness of impending death with his wife. He described an occasion when his wife, conscious that death was near, had clearly wished to talk about her fears and sadness. His response had been to rebuke her for being morbid. He subsequently felt that it had been his own fears that made him so reluctant for her to share her thoughts with him.

*... 'She said, "If I died tomorrow I've had a good life", "What the hell do you mean? If you talk like that", I said, "I'll push you out of bed!" But now I wish I'd stopped and spoke to her. She might have wanted to talk about it...' [61]*

In a survey in Sweden of 429 parents who had experienced the death of a child who was diagnosed with cancer before the age of 17 and died before the age of 25; 147 talked with their child about death [106]. None of them regretted it. In contrast, 69 of 258 parents who did not talk with their child about death regretted it (27%). Among parents who sensed their child's awareness of their imminent death, 113 of 225 (50%) did not talk about death, and 47% of these regretted it. In a re-analysis of interview transcripts collated from studies in the USA that were originally designed to describe elements of

quality end of life care [107], it was apparent that when dying patients talked about their death with their loved ones, they seemed to feel less isolated in the face of death. These discussions also relieved their loved ones of having to make decisions alone.

A systematic review concluded that people who felt prepared for the death of a loved one had a lower risk of experiencing a complicated grief reaction than those who had not prepared [108]. In a retrospective study of people using on-line bereavement forums, being able to have the conversations they wanted with their partner before death seemed to reduce the risk of complicated grief, although the amount of communication did not have an effect in itself [109]. Other studies have looked at whether discussing end of life wishes while well might cause harm, and have found no evidence for this. Research from the USA in teenagers with HIV infection showed that the young people were willing to talk about end of life care and that having those conversations did not increase levels of depression or anxiety [110, 111]. Research in people with terminal cancer showed that having end of life discussions with doctors was not associated with patients feeling depressed, worried, sad or scared [91].

Planning and discussing end of life wishes might also help spouses to feel more understood by each other. In a study of married couples in their mid-60s in the USA [112], respondents who did any formal planning or had talked to anybody about their end of life preferences were more likely to feel extremely well understood following end of life discussions with their spouse; and to have a spouse who felt extremely well understood. A study published in 1999, which interviewed people living with HIV, showed that advance care planning with loved ones helped patients to face death, and gave them a way to think about death and dying [113].

## **2.8 Public attitudes towards and practice of preparing for and talking about death**

The results of quantitative surveys conducted in the UK suggest that the majority of people agree with view of policy-makers that death and dying are not discussed often or openly enough, and that it would be good thing if this were to change. In a 2012 national survey commissioned by Dying Matters [7], 78% of respondents agreed with the statement: "If people in Britain felt more comfortable discussing

dying, death and bereavement, it would be easier to get end of life wishes met". This varied slightly by age group, increasing gradually from 65% in those aged 18-24 to 89% in those aged 65 and over. In a survey published in 2005, in which 129 people aged 55 to 74 and 127 people aged over 75 were recruited from GP registers in London [114], the majority agreed with the statement: "I wish that death and dying were more openly discussed within society".

Survey respondents also tended to agree with statements that talking about death was taboo, or something which people felt uncomfortable with. In a survey commissioned by Marie Curie Cancer Care in 2004 [115], 79% responded 'yes' to the question: "Do you think death is a taboo subject for the majority of people in the UK?". In the 2012 Dying Matters Survey, 71% agreed with the statement, "People in Britain are uncomfortable discussing dying, death and bereavement". This varied between 59% in those aged 18 to 20 to 78% in those aged 65 or over. The perception that people are uncomfortable talking about death also seemed to generate some concern that this might affect their ability to access support from other people when they might need it; 63% said they would be either very concerned or fairly concerned that, if they were told they were dying, other people would avoid talking to them about the fact that they were dying [7].

Although there was a common perception that people were uncomfortable talking about death, the majority of survey participants reported that they, personally, were comfortable talking about death. In the Dying Matters 2012 survey, 71% agreed that they felt fairly comfortable or very comfortable talking about death with friends and relatives [7]; which compared with 57% who reported being comfortable talking about sex and 80% who reported comfortable talking about politics. The proportion reporting being comfortable talking about death was up slightly from 68% in a 2009 survey [8], and 65% in a 2006 survey [116]. A survey undertaken in the East of England in 2010 specifically asked how comfortable respondents felt about talking about their own death [117]; 69% reported being either fairly comfortable or very comfortable talking about their own death, compared with 73% who were comfortable talking about death in general. In all the surveys, a slightly higher proportion of those aged 45 and over, compared to those under the age of 45, reported being comfortable talking about death [7, 8, 116, 117]. In another survey, undertaken in Canada [118, 119], only 9% of 226 participants agreed with the statement that 'end of life is too sensitive a topic to talk about'. This dichotomy between individuals' reports of how comfortable they are able talking about death and how comfortable they perceive other people to be has also been observed in

other studies. For example, in a study of young people living with HIV and their parents, significantly more young people (67%) reported being comfortable talking about dying than their parents perceived (41%) [111]. In research undertaken in the 1960s, most people reported that they would want to be told if they were dying, yet many also suggested that other people might not want to know [120].

Although the majority of people report being comfortable talking about death, many people in the UK have not talked about their own end of life wishes. For example, in the 2012 Dying Matters survey [7], only 50% of respondents reported that they had told anybody whether they would like to be buried or cremated and only 37% reported that they had made a will. Prevalence of having a will varied widely by age (from 2% in the 18 to 24 age group to 69% in the 65 and older group) and social class (from 23% in classes D and E to 49% in classes A and B). Other surveys reported very similar findings [8, 116]. Surveys which included participants aged over 75 as a separate category reported the proportion with a will at between 81% [117] an 83% [8], suggesting that the majority of people who die in old age in the UK have a will at the time of their death.

In a survey of randomly selected households in South Dakota, USA, most respondents thought that preparation for end of life is very important, yet far fewer had taken any steps to ensure their end of life wishes would be known or met [121]. For example, 71% said it was important to have their finances in order, although only 49% had written a will. Most respondents said that they would prefer other people to initiate conversations about end of life; most often their family or spouse, although some suggested that doctors, members of the clergy friends or lawyers might do this [121]. In focus groups of older people in Sheffield, England, the majority of participants suggested that doctors should initiate discussions of end of life treatment and care with seriously ill patients, and that this might open up an opportunity for patients and their families to talk about dying and death together [122].

Perhaps as a result of so many people not talking about their end of life wishes, 27% of people said that if somebody close to them were to die, they would not know their end of life wishes [7]. This varied by age from 36% of those aged 18 to 24 to 19% in those age 65 and older. In addition, 35% said that they would not be able to afford the funeral, ranging from 55% of those aged 18 to 24 to 14% of those aged 65 and over [7]. Unsurprisingly, this also varied by social class, with 49% in classes D and E stating that they would not be able to afford the funeral, compared with 23%



in classes A and B. Thirty percent said that they would not know where to go for support if somebody close to them died; again the proportions were higher for younger respondents and those with a lower social class [7].

When asked what would motivate them to plan for the end of their life, the most frequent response was 'to make things easier for my family' (61% in one survey [8]; 79% in another [117]). Interestingly, in a qualitative study of Aboriginal people in rural Australia, this was also the most frequent reason for advance care planning [123]. In the UK survey, smaller proportions said they would be motivated by the thought of getting the funeral they want (8% [8] and 24% [117]) or getting the right care and support while they were dying (14% [7] and 4% [117]).

## **2.9 Specific barriers to preparing for and talking about death**

In addition to the societal norm of not often discussing death [81], a number of specific barriers have been identified which may prevent some individuals from talking to the people close to them about own end of life wishes. When people in the UK who had never discussed their end of life wishes were asked why [8, 117], the most common reason given was that death seemed a long way off. In research with elderly care home residents [124] and kidney dialysis patients [80], many felt they were too busy with day to day life to consider end of life wishes. Many people with COPD preferred to concentrate on staying alive than planning for their death [125]. Lack of knowledge of the options may be an issue. In Ireland, 71% of people had not heard of an advance directive [126], and research from the USA showed that the main difference between those who did and did not complete an advance directive was an understanding of the documents and their importance [127]. This may in part be related to the complex medical and legal terminology often used by professionals. Some people may also feel that they do not have genuine choices about end of life care; many care home residents in the UK thought that the decision on whether they could stay in place at the end of their life would be made by other people [124].

Some people find contemplating their own death upsetting or frightening [116]. In a UK-wide survey [8], 10% of people who had not discussed their end of life wishes said it was because they did not feel comfortable doing so. As it was a purely quantitative survey, there was no information as to why they might not have felt comfortable. Others find having these conversations with people close to them difficult [128]. In a survey conducted in the East of England, 21% of people who had

not discussed their end of life wishes were concerned that doing so might upset other people [117]. In research from the UK and USA, older people sometimes said they would like to talk to their families about their end of life wishes but their families did not want to have those conversations. In a UK survey, 14% of people aged over 55 who had not discussed their end of life wishes said it was because other people did not want to [8]. In the USA, older adults and their adult children found it difficult to find time to talk when families lived at a distance [129].

## **2.10 The Cheshire Living Well Dying Well Public Health Programme**

During 2009, St Luke's (Cheshire) Hospice approached representatives of community groups and voluntary sector organisations related to youth, older people, faith, social care, LGBT community, health and housing to discuss a public health approach to end of life issues [130]. In Spring 2010, the hospice employed an external facilitator from the Conversations for Life organisation [131] to facilitate two exploratory workshops attended by the community representatives and members of the Strategic Health Authority, cancer networks, social and health care and a local MP.

These workshops identified a need to engage with the local population to support their ability to conduct appropriate conversations within their social networks about end of life issues. This would empower them to act in ways that would serve them and the people close to them in times of serious illness and death, for example, by making a will or supporting a grieving neighbour. A commitment was made to develop an End of Life Public Health approach based on education about death and dying. The Cheshire Living Well Dying Well (CLWDW) public health programme was born from this commitment, supported by a grant from Macmillan Cancer Support.

In May 2011, a dedicated public health lead was employed to drive forward the agenda. A partnership development process was undertaken to encourage representation across different sectors and to identify opportunities for individuals and organisations to contribute to the implementation. The name of the programme was agreed and its over-arching aim agreed as *"to improve health and wellbeing by supporting a change in knowledge, attitude and behaviour towards life, age, death and loss and through this make living well, ageing well, dying well and grieving well the norm."* The public health lead developed a visual concept model to convey the vision and concepts to the variety of potential community partners [132].

The central tenet of the model was 'living well' and that living well, ageing well, dying well and grieving well were all inextricably linked. Impact can occur from the outer layers of the circle inwards and equally from the reverse direction. For example, policy changes related to bereavement will impact on individuals, families and communities and how they live, age, grieve and die. Equally, an individual who considers and records wishes for the end of their life will have an impact on their own wellbeing and that of those close to them and how they live, age, grieve and die.



**Figure 1: Visual concept model of the Cheshire Living Well, Dying Well Public Health Programme**

Following consultation, the CLWDW Partnership structure was confirmed, partnership representatives were recognised as CLWDW Champions, and six strategic work areas and their objectives were agreed. These strategic work areas and their objectives are listed in Table 1.

The CLWDW Partnership was officially launched with an event in May 2012. There are currently 172 CLWDW Champions representing 72 public private, voluntary and community organisations.

St Luke's Hospice supported this PhD research to establish the effectiveness of one of the CLWDW resources; a community intervention to increase conversations and change behaviour about end of life issues, as well as examine the wider context for this work in order to inform future development of both this programme and others.

**Table 1: Strategic work area of the CLWDW Public Health Programme**

<b>Strategic Work Area</b>	<b>Objective</b>
<i>CLWDW Public Health Partnership and Strategy Development</i>	Embed a public health partnership approach to ageing, death, dying and loss at a local/ regional/ national level
<i>EOL Financial Housekeeping and Future Planning</i>	Motivate and assist people to make plans, record wishes and have more open discussions about ageing, death, dying and loss
<i>Resource Development</i>	Create and develop a toolkit of resources to enable effective and appropriate CLWDW public health interventions
<i>Public Education, Learning and Development</i>	Raise awareness and increase knowledge and understanding as to why Living Well, Dying Well is a public health issue
<i>Compassionate Communities</i>	Build community capacity for End of Life Care via informal health from relative and friends or via formalised volunteering
<i>Healthy Workplaces / businesses</i>	Encourage workplaces/ businesses to review organisational approaches and recognise Living Well Dying Well as a public health issue

### **3. Systematic literature review**

A systematic literature review was undertaken to establish current evidence for the effectiveness of different public health interventions in encouraging members of the general population to consider, and to discuss with those close to them, their preferences for end of life care or what they wish to happen after their death. A version of this review was published in BMC Palliative Care in 2013 [133].

#### **3.1 Methods**

##### **Inclusion criteria**

Studies were included if they described and evaluated a community-based intervention designed either to encourage people to consider, and to discuss with those closest to them, their preferences for end of life care or what they would wish to happen after death, or to address known barriers to these discussions. Known barriers to discussions are described in the Background Chapter 2.8 and include:

- Not considering the issue worth considering at the moment
- Lack of knowledge of the options available
- Fear or distress associated with thinking about death or dying
- Difficulty persuading significant others to participate in these conversations, or fear of upsetting others

Included studies had to report on at least one outcome relating to attitude or behaviour change in the target group, or perceptions of the intervention as reported by the target group. Direct observations by researchers or staff delivering the interventions were acceptable if quantified or supported by specific examples.

To ensure that data was only included in the review if it was directly relevant to the review question, studies were excluded if they included only people with a life-limiting illness; evaluated only interventions designed specifically to facilitate communication of end of life preferences between patients and healthcare staff; or were intended only to facilitate the completion of advance care planning documents.

## **Search criteria and methods**

An initial search was conducted using Scopus. The search terms used were:

('Dying' OR 'End of Life') AND ('Planning' OR 'Public Health' OR 'Health Promoting Palliative Care' or 'Health Promotion' or 'Discussion' or 'Talk' or 'Conversation' or 'Communication')

Terms listed in: article title, abstract or keyword

Dates: Jan 1, 2000 to June 6, 2015.

Limit to: Health Sciences and Social Sciences and Humanities

A Google search using the same search terms was used to identify books and websites that were not included within academic databases.

Following the application of inclusion criteria, academic experts working in the field of public health and palliative care were contacted and asked about any additional relevant published work which they knew about.

## **Selection of included studies**

All publications which appeared to cover a related topic were retrieved, read and the reference lists were scanned for further relevant publications. Studies were then selected by application of the inclusion criteria.

## **Data extraction and analysis**

Each study was summarised by study intervention, target group, research or evaluation methods, and findings. Findings were categorised as either:

- Primary outcomes, relating to evidence of encouraging discussions between participating targets and people close to them, or;
- Secondary outcomes relating either to addressing known barriers to discussion or to intermediate outcomes such as attendance at an event, evidence of engagement in a process, or participants' ratings of the intervention.

The quality of the included studies was assessed using the system developed by Hawker and Payne [134] for reviews including studies using a diversity of methods (Appendix 1). Studies were scored on nine criteria, using the following scoring

system: Good=4; Fair=3; Poor=2; Very Poor=1. Total scores were calculated for each study, where 9=lowest possible (very poor) and 36=highest possible (very good). Where a study was described in more than one paper, the best description available was used. Where a criterion was not relevant to the study, for example, ethical approval for an evaluation, the study was scored as 'Good' for that criterion.

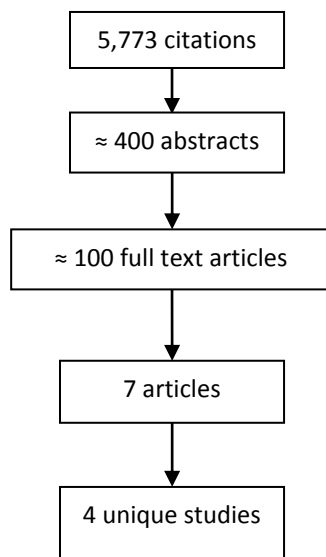
Data extraction and analysis were undertaken by Katharine Abba (KA) and Mari Lloyd-Williams (ML-W) and reviewed by KA, ML-W, Paula Byrne and Siobhan Horton. No attempt was made to combine study results, because the small number of studies and wide range of interventions reported made this inappropriate.

## **3.2 Findings**

### **Search results**

The Scopus search returned 5,773 citations. The Google search revealed around 636 million results, of which the first 40 pages were screened. The experts contacted were not aware of any additional relevant studies. In many cases it was difficult to determine the content of an article from its title; as a result over 400 abstracts were scanned, and over 100 full-text articles and two books were retrieved. All potentially relevant articles were either written in English or had an abstract in English. The most common reasons for exclusion of studies were that they were not intervention studies, or that the target group were people already known to have a life-limiting illness, usually involving advance care planning with healthcare staff. A book chapter describing various projects undertaken by a London hospice to engage local communities in discussion about life, death and bereavement was excluded because it did not provide enough detail for us to be able to extract data relating to specific interventions and outcomes [135].

From the retrieved studies, five studies, described within seven journal articles and one book chapter, were included. Four were identified by the Scopus search and one (a book chapter) was identified through the Google search. The selection of included studies identified through the Scopus search is illustrated in Figure 2.



**Figure 2: flowchart illustrating the selection of included studies identified through the Scopus search**

### **Characteristics of included studies**

Four of the included studies were undertaken in the UK and one was undertaken in Japan. The aims, interventions, methods and outcome measures of the included studies varied widely. The included studies, and the reasons for their inclusion, are summarised in Table 2.

Only one study (Hickey et al 2012 [136]) evaluated an intervention designed to directly influence people to discuss their end of life preferences with those closest to them. This was a public information ‘roadshow’ with an opportunity for people attending to complete a questionnaire together. Two further studies (Seymour and Clarke 2009 [137], Sanders et al 2008 [138]) were designed primarily to increase knowledge of end of life planning, although the interventions themselves included opportunities for group discussion with peers. One study used public lectures to raise awareness of options for end of life care (Miyashita et al 2008[139, 140]) and another was an arts-based project designed to educate school pupils about the work of a hospice and the realities of dying (Hartley 2011 [141]).

The methods used to evaluate the interventions included qualitative interviews; qualitative analysis of free text comments on questionnaires; mixed methods of questionnaires, telephone interviews and focus groups; a quantitative ‘before and



after' questionnaire survey; and direct observation by the people delivering the interventions.

### **Quality of included studies**

In general, the quality of included studies was assessed to be good, with quality scores ranging from 29 to 36 (Table 3). However, this hides significant weaknesses in the studies' methodologies as they relate to the review question. Scores were boosted by the decision to assign maximum scores for criteria that were not relevant for particular studies. One of the studies in particular (Hickey et al 2012 [136]) was a simple descriptive observational study and many of the items included in the standard quality assessment tool used were not relevant. We also scored each study as 'good' in terms of usefulness because of the scarcity of other evidence in the field. The majority of included studies were well reported, which boosted their score using the system selected, which assesses quality of reporting as much as quality of research design and conduct. The studies also tended to score highly for methodology because they used an appropriate and well described method; however, methods tended to be limited in breadth and scope, and most were designed primarily to answer a slightly different question to that of the review. For example, one study used a purely quantitative questionnaire survey, meaning that more subtle or unexpected effects may not have been captured. Another used open text responses from questionnaires administered immediately following an intervention [141], therefore limiting the study to participants' immediate observations, and those which could be written in a small space.

### **Findings**

The findings are presented separately for primary and secondary outcomes.

#### ***Primary Outcomes***

Only one study reported on the primary outcome of the review. Hickey 2012 [136] reported that many people who completed an informal questionnaire survey together at a public information road show immediately engaged in discussion together about their end of life preferences, as observed by people who were facilitating the questionnaire. They gave the following example: "a married couple who had never spoken about their end of life preferences agreed to complete a questionnaire supported by a professional with palliative care experience. Both were surprised at

the wishes of the other and continued in conversation with one another about these issues, with no need for further facilitation."

### ***Secondary outcomes***

#### ***Engagement, attendance, and participant views***

Hickey 2013 [136] reported that the public information 'roadshows', which had been well advertised and were located in two busy town centres in the South East of England, were well attended by people of all ages and more than 450 people participated in a facilitated questionnaire survey, approximately 70% of them female. It was also reported that many people were able to access information, support and referral as a result of completing the questionnaire, although this observation was not quantified.

An action research study to pilot an older person's peer education project in the North of England (Seymour and Clarke 2009 [142] demonstrated that it was feasible to develop a high-quality educational booklet on end of life planning in collaboration between academic staff and older people from voluntary agencies. The booklet covered end of life choices and planning, ethical issues, caring and coping, and loss and bereavement. After training, older volunteers also helped to facilitate a series of three end of life planning workshops for peers, which were each attended by six to eight older people. In structured questionnaires (n=12) and semi-structured telephone interviews (n=8), older people attending the workshops said they considered the educational booklet provided, and the opportunity to discuss issues with their peers, to be worthwhile and useful. A focus group with peer educators (volunteers) helping to design and deliver the project revealed that they found the experience rewarding, and that they thought they had learned a lot, but most did not feel confident enough to lead the workshops and preferred the role of assistant.

A London project, bringing together hospice users and school pupils to work together on an arts project to present to parents (Hartley 2012 [141]), reported being successfully run over 40 times, with a range of different schools and age groups. It was observed that children asked questions and hospice users talked freely about the experience of illness and dying. Most participants also completed an evaluation questionnaire at the end of the particular project they were involved in. In free-text responses, participants (children, parents and hospice users) reported various positive personal outcomes. For example a ten year old child wrote:

*“...my grandmother died at the hospice and I wasn’t allowed to go...I enjoyed seeing that it was OK really’, a parent wrote ‘I’ve lived in this area all my life and have been too afraid to come into the building...is it possible to volunteer some of my time to continue to help?’ and a hospice user wrote “I always felt nervous talking to my children about what was happening to me – couldn’t find the words and didn’t want to upset them...watching people talk to each other here gives me the confidence to talk to my own family”.*

A public lecture programme in Japan, on the topic of home-based end of life care (Miyashita et al 2008 [139, 140]) was attended by 607 people, although the lectures were combined with regional public meetings on other topics. The mean age of attendees was 66 years, 67% were female, and 84% reported excellent or good health. Most (99%) reported having already had discussions of end of life concerns with family. Of 595 people who attended; 95% said it was interesting, 96% said it was easy to understand, 95% said it would be of help in the future and 94% said it provided the opportunity to consider end of life medical treatment.

In a qualitative interview study of people in the UK who had attended an ‘Expert Patients’ course on self-management of a long term illness (Sanders et al 2009 [138]), the majority said that the subject of advance care planning was inappropriate within that context. Information materials for the Expert Patient’s course did not make any reference to the module of advance care planning, and therefore participants were not expecting it. Some, who had recently been bereaved, felt distressed and others that it was out of context with the course, which was about managing their health condition in a positive way. Others thought that there was not enough support available to deal with the sensitive issues raised, or that there was not enough time to discuss the issues in sufficient detail.

### Normalisation of death

Content analysis of questionnaires completed by participants in the hospice-schools arts programme already described (Hartley 2012 [135]) identified four major themes: changing ideas and attitudes towards hospices (pupils), normalising death and dying (pupils); enjoyment that patients got from acting as educators (patients), and creating a relationship between the hospice and community (pupils and parents). The following quote was given by a 16 year old pupil.

*“....we thought they'd all be miserable and depressed.....but it was just like being with your friends.....we laughed and cried and sometimes felt afraid, normal things....”*

### Belief in the possibility of dying at home

In a questionnaire survey of 595 people attending the public lectures about home-based care in Japan, prior to the lecture, 9% of participants stated that home death was possible, 53% said it was impossible and 33% were unsure. Immediately after the lecture, 34% stated that home death was possible, 27% said it was impossible and 32% were unsure. This represented a significant change from 'impossible' to 'possible' ( $P = 0.001$ ). Of these 595 participants, 424 also completed a questionnaire six months after the lecture. In this sample, 10% stated that home death was possible before the lecture, this rose to 37% immediately after the lecture but after six months later it fell to 12%. The difference between baseline and last follow up was not statistically significant ( $P=0.12$ ).

## **3.3 Discussion**

Only five studies were identified that met the inclusion criteria, despite a wide search and also speaking to key people in the field to ensure relevant papers had not been omitted. It is possible that other published studies were missed, as articles may not have been indexed as expected. The initial search was limited to Scopus and Google and to studies published in 2000 or later. This was because it was expected to be a relatively recent field of study, and it was also necessary to limit the number of irrelevant citations in a search which already had a low specificity. However, the reference lists of identified studies were scanned for earlier studies and findings do suggest a genuine scarcity of research evidence in this area. A published overview of 'Compassionate Communities' projects in England [24], which identified several projects with objectives aligned to this review, described most as having been recently set up, having a small scope or limited funding. Under these circumstances it is not surprising that there is little published evidence available.

The studies available presented fairly limited evidence for what interventions are effective in encouraging people who are well to discuss their end of life wishes with those closest to them. The majority of studies were designed primarily to answer slightly different questions to that of this review, and some seemed to have been

severely limited by the funding available. Only one study reported on the primary outcome of this review, and this was quite low quality, almost anecdotal evidence, based on observations made during an intervention. Two other studies reported observations that interventions appeared to help to facilitate conversations about end of life planning (older people) or death and dying in general (school pupils), but these conversations occurred among peers rather than close family and friends. The methods employed by studies were also often quite limited in scope, for example, most studies used only very short-term follow-up, while the true effects of an intervention may take some time to be felt. Studies which used only quantitative methods or only free text responses from self-administered questionnaire may not have captured all of the subtleties of effects, while one study which used in-depth questionnaires concentrated on the acceptability of an intervention rather than its outcomes.

Despite the paucity of evidence, some useful findings have been identified. In one study, couples attending a public information 'roadshow' event, who were engaged in completing an informal end of life planning questionnaire survey together, were observed to often become involved in discussions of end of life wishes between themselves, sometimes for the first time. Although this finding is not quantified, and comes from a relatively poor quality descriptive observational study, the evidence is direct and cannot be discounted.

Another intervention was shown to be successful in engaging older people in discussion about end of life planning with peers. Older volunteers were employed as peer educators alongside academic staff, resulting in a user-friendly end-of-life planning information booklet and an associated workshop that was valued by the participants. A project bringing together school children and hospice patients to work together on an arts project reported facilitating natural conversations between school pupils and hospice users, and in the process helping to normalise death and dying for children and young people. Normalising death may help allay some of the fears that can make talking about death and dying more difficult, and hence projects like this might facilitate discussions about end of life in the long term.

An end of life care planning module within an 'Expert Patient' education programme, designed to help patients to self-manage conditions that were not necessarily life-limiting, was less successful in engaging people and facilitating discussion. The majority of participants felt that the topic was inappropriate or distressing, and did not wish to discuss it. This suggests that context might be very important. It is also

of note that the subjects of this study had not been informed that the end of life planning module would be included in the programme, which might also raise ethical issues of choice and consent.

An intervention using public lectures to try to change beliefs in the possibilities for end of life care had limited success. The lectures attracted mainly people who had already discussed their end of life preferences with family, and did not significantly change beliefs about the possibilities for end of life care beyond the very short term. It is possible that a more participatory approach would have been more successful than the passive lecture format used.

In summary this review has shown that there is very little research evidence available as to the types of intervention which can encourage people who are well to consider, and to discuss with those close to them, their preferences for end of life care or what they wish to happen after their death. It has, however, confirmed that, in the right circumstances, people appreciate the opportunity to discuss end of life issues, suggested that participatory approaches may be more successful than passive information-giving, and highlighted the importance of medium and long-term follow-up when evaluating the impact of these studies.

**Table 2: Summary of included studies**

Study ID and Location	Aim of intervention	Intervention methods	Reason for inclusion	Evaluation methods	Main Findings
Miyashita et al 2008[139, 140]  Fukushima, Japan	To raise awareness among the general public of the possibility of receiving appropriate support to enable dying at home	One-hour lectures delivered by a physician at a series of public meetings. Lectures covered treatment options and resources available to people who were dying at home.  Target group: self-selected by open advertisement	Addressed known barrier: lack of knowledge of the options available	Quantitative questionnaire survey of attendees before, immediately after and six months after the lecture.  607 people attended, 595 completed questionnaire before and immediately after the lecture, 424 at all three time-points.	Secondary outcomes  99% of attendees reported previously discussing end of life concerns with family.  95% said the lectures would help in the future.  10% of those completed all three questionnaires stated that home death was possible before the lecture, rising to 37% immediately following the lecture but falling back to 12% after 6 months.
Seymour and Clarke et al 2009[137]  North of England, UK	To engage and educate older people on end of life planning options and processes; as both educators and educated.	Collaboration between academic staff and older people from voluntary agencies to develop an information booklet and peer-education programme designed to facilitate peer to peer discussions.  Target group: people over the age of 65	Addressed known barriers: lack of knowledge of the options available and lack of opportunity for discussion	Questionnaires (n=12) and telephone (n=8) interviews of people who attended the workshops  Focus groups of the peer educators	Secondary outcomes  In questionnaires and interviews workshop participants reported the booklet and opportunity to discuss issues with their peers to be worthwhile and useful.  In focus groups the peer educators said they found the experience enjoyable and rewarding but most did not feel confident enough to lead a workshop themselves.

Hartley 2012[141]  London, UK	To change perceptions of death and dying among school children and their families	Project which brought school pupils and hospice users together to answer children's questions and work on an arts project of their choice, and which ends with a presentation of the project to parents.  Target group: school pupils, teachers, parents and hospice users	Addressed known barriers: fear of death and dying, lack of knowledge of the options available	Ongoing evaluation: questionnaires, including space for free text, completed by all participants.  The exact sample size was unstated, although by the point of analysis, as the project had been run over 40 times.	Secondary outcomes  Qualitative analysis of free text responses identified 'normalising death and dying' as a major theme for the children involved.  Example: "....we thought they'd all be miserable and depressed.....but it was just like being with your friends.....we laughed and cried and sometimes felt afraid, normal things...." (16 year old pupil)
Sanders et al 2008[138]  Various locations, UK	To educate people with long term health condition about end of life care planning	Short learning module within a much wider generic 'expert patient' course designed to teach people how to better manage any long term health condition  Target group: People diagnosed any long term health condition, who self-referred onto the course. Participants were not made aware of the end of life care planning module in advance of the course.	Addressed known barrier: lack of knowledge of the options available	Qualitative analysis of interviews with people who attended the course, using purposive sampling for maximum variation and across all areas of England (n=31).	Secondary outcomes  The majority of participants expressed the opinion that the advance care planning module was inappropriate in the context it was introduced. Some people, who had recently been bereaved, felt distressed during the session.



Hickey at al 2012[136]  Essex, UK	To educate and engage the public in discussing end of life issues	Well-advertised public information 'roadshows' were held in two busy town centres. People who attended were invited to complete an end of life planning questionnaire, with support available to respond to any queries arising.  Target group: members of the public attending a town centre outdoor event with an end of life theme	Aimed directly to encourage people to consider and discussed their end of life preferences; also addressed the known barrier of lack of knowledge of the options available.	Record keeping and observation of staff who delivered the intervention	<p>Secondary outcomes</p> <p>The events were reported to be well attended by people of all ages. More than 450 people completed questionnaires, 70% of them female.</p> <p>Primary outcomes</p> <p>Staff observed the process of completing questionnaires help start discussions about end of life wishes among people who completed the activity together. The authors also reported that many people also accessed information, support and referral as a result.</p>
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**Table 3: Quality assessment of included studies**

Study ID	Aspect	Assessment	Score	Comments
<b>Miyashita et al 2008</b>	Abstract and title	Good	4	
	Introduction and Aims	Good	4	
	Method and data	Good	4	Questionnaires not presented but described in detail
	Sampling	Good	4	
	Data analysis	Good	4	
	Ethics and bias	Good	4	
	Findings/ results	Good	4	
	Transferability/ generalisability	Good	4	
	Implications and usefulness	Good	4	
	<b>Total</b>		<b>36</b>	
<b>Seymour and Clarke et al 2009</b>	Abstract and title	Good	4	
	Introduction and Aims	Good	4	
	Method and data	Good	4	
	Sampling	Good	4	
	Data analysis	Good	4	
	Ethics and bias	Fair	3	Ethical approval not relevant, as it was an evaluation study. Presents discussion of limitations.
	Findings/ results	Good	4	
	Transferability/ generalisability	Good	4	
	Implications and usefulness	Good	4	
	<b>Total</b>		<b>35</b>	

<b>Hartley 2012</b>	Abstract and title	Poor	1	Abstract not normally expected in the format of a book chapter
	Introduction and Aims	Good	4	
	Method and data	Fair	3	Questionnaires not presented
	Sampling	Good	4	
	Data analysis	Fair	3	Described simply as 'content analysis'
	Ethics and bias	Fair	3	Ethical approval not relevant; evaluation study
	Findings/ results	Good	4	
	Transferability/ generalisability	Good	4	
	Implications and usefulness	Good	4	
	<b>Total</b>		<b>30</b>	
<b>Sanders et al 2008</b>	Abstract and title	Good	4	
	Introduction and Aims	Good	4	
	Method and data	Good	4	
	Sampling	Good	4	
	Data analysis	Good	4	
	Ethics and bias	Fair	3	Ethical approval not relevant; evaluation study
	Findings/ results	Good	4	
	Transferability/ generalisability	Good	4	
	Implications and usefulness	Good	4	Focussed on acceptability rather than outcomes
	<b>Total</b>		<b>35</b>	

<b>Hickey 2012</b>	Abstract and title	Fair	3	
	Introduction and Aims	Fair	3	
	Method and data	Fair	3	Simple observations reported, but not clear who did the observing
	Sampling	Good	4	Not applicable, descriptive observational study
	Data analysis	Fair	3	Not applicable, descriptive observational study
	Ethics and bias	Fair	3	Intervention and evaluation methods had few ethical and bias issues
	Findings/ results	Poor	2	Did not quantify the numbers of people who engaged in discussion and provided only one example; however this was not the main topic of the paper
	Transferability/ generalisability	Good	4	
	Implications and usefulness	Good	4	
	<b>Total</b>		<b>29</b>	

## **4. Methodology**

### **4.1 Developing the research question and methodology**

This thesis seeks to contribute towards answering the research question “How can public health activities encourage planning for and discussion of issues relating to end of life and death as a way of minimising distress associated with death, dying and bereavement?”. Within this overall question were two separate research objectives; the first was to research the impact of the innovative interventions delivered by the CLWDW Public Health Programme (as described in the Introduction); the second was to conduct a linked study into the relevant views and priorities of the general public. Within this remit, the specific research questions were refined and the research methodology developed. The process of refining the research questions was undertaken in parallel with and following the initial literature review, in consultation with the primary supervisor and external advisor.

The first objective corresponded to a clear research question: “What was the impact of the innovative public health interventions delivered by CLWDW public health programme?”. To generate useful research knowledge that could be applied in different situations, it was important to investigate not just what the impacts were, but also how and why the impacts were achieved. It was hypothesised that the interventions might have the effect of making people feel more comfortable about talking about death, or act as a ‘prompt’ for people to take appropriate actions regarding end of life planning and communication. It was also hypothesised that the interventions might have different effects on people with different demographic and personal characteristics. The research questions and sub-questions were therefore devised as:

- What was the impact of the innovative CLWDW public health interventions and how was this impact achieved?
  - Who attended the interventions and what previous experience did they have in planning for and talking about death?
  - What were attendees’ views of the intervention?
  - What effect did the intervention have on how comfortable attendees felt about talking about death?
  - What actions, if any, did attendees take as a result of attending the interventions?

- What were the relationships between taking actions as a result of the intervention and the other factors described?

The second research objective was to obtain knowledge of the views and priorities of the general public regarding planning for and talking about death. This was intended to begin to fill the most important gaps in knowledge, based on future practical application, and to provide some context in which the results of the CLWDW public health interventions might be better understood and explained. The development of more precise research questions within this objective took account of gaps in knowledge identified through the literature review; the interests of the researcher, supervisors and advisors; and the possibilities for investigation within the resources available.

The initial literature review (see Background Chapter 2) found almost no research into underlying societal attitudes to, or lived experiences of, talking or not talking about death in different situations. What little research had been published was based mainly on quantitative surveys. These provide descriptive statistics relating to a narrow range of pre-defined questions, but do not capture subtleties or ambiguities of thinking, or ideas not considered by the researchers. There has been little research into the thoughts, feelings and experience behind the statistics, or into needs and priorities as identified by the researched, rather than the researchers. There has also been little theoretical consistency. Media [143, 144], policy-makers [18] and some sociologists [80] describe death as a 'taboo' subject, yet in population studies the majority of participants report being comfortable with the idea of talking about death [7, 8].

Because it is such a little-researched and little understood area, it seemed appropriate that the research area should be expansive, rather than focusing on one small aspect. The research questions were therefore kept broad. The main research question was formulated as: "What are the views and priorities of the general population regarding talking about and planning for death in the context of reducing distress associated with death, dying and bereavement?". Within this question four sub-questions were formulated, to reflect what appeared to be the most important gaps in current knowledge.

- What are the views and priorities of the general population regarding talking about and planning for death in the context of reducing distress associated with death, dying and bereavement?

- What importance do people attach to talking or not talking about death, and in what situations?
  - What experiences have led them to feel this way?
- What are the personal and social factors that act as barriers to talking about death, dying or bereavement?
  - How do people overcome these?
- What societal factors act as barriers to open discussion of issues relating to death, dying and bereavement?
  - Where does the common perception of a 'taboo' come from?
- What ideas do participants have about public health interventions to facilitate appropriate planning and communication relating to death, dying and bereavement?

## **4.2 Mode of enquiry**

A mixed methods mode of enquiry was used, combining quantitative and qualitative methodological approaches to answer and integrate the two different research questions included within the thesis. The mixed methods, or mixed model, approach is considered by some to be a 'third paradigm' in social research [145], because it evolved after quantitative and then qualitative methodologies became established. It is considered by others to be part of a continuum that includes qualitative, quantitative and mixed methods [146]. The two main component questions seemed clearly to be best suited to mainly quantitative and mainly qualitative enquiry respectively. As the mixed methods approach is the only approach which can accommodate both paradigms within one research project, it was the only approach considered for this thesis.

Mixed methods have been used in social research since the early twentieth century, but the approach has been seen as a research paradigm in its own right from the 1990s onwards [147], following the quantitative/positivist versus qualitative/interpretivist methodological/epistemological debate of the 1980s known as the 'paradigm wars'. Mixed methods as an approach has been described by Tashakkori and Teddlie as having the following defining characteristics [148, 149].

- Using quantitative and qualitative methods in the same research project
- A research design that clearly specifies the sequencing and priority that is given to the quantitative and qualitative elements of data collection and analysis

- An explicit account of the manner in which the quantitative and qualitative aspects of the research relate to each other
- Pragmatism as the philosophical underpinning for the research

The 'mixing' may be the parallel or sequential use of different methods, or it may be that different methods are fully integrated in a single analysis [150]. There has been some debate as to whether the mixing of methods from two paradigms can be valid, considering the very different underlying assumptions which usually underpin the two approaches. Where two methods are highly integrated, for example, where text from open interviews is coded into themes which are then included in a statistical analysis, the mixing of paradigms can cause problems with the interpretation of the findings, as the underlying assumptions become unclear [147, 151]. Where two methods are not integrated at all, there is a risk that it might be seen simply as two separate studies about the same question.

In this thesis, the two approaches correspond to two distinct research strands, each of which could also stand alone as a study in its own right. Each strand was analysed separately so as to remain true to its own epistemological and design requirements [152], and the results of each strand were discussed separately in the context of their own epistemology. The quantitative strand provided the sampling base for the qualitative strand; making it a sequential study, although the conduct of the qualitative strand was not dependent on the findings of the quantitative strand. However, it was intended that the knowledge generated by the two strands together be greater than simply the sum of the two. The mixing of methods occurred as the findings from the two different research strands were considered together when drawing overall inferences, and the overall conclusions were based on this analysis. The underlying philosophy of the approach used was one of pragmatism (see Epistemological Approach section 4.3); in summary of selecting the most appropriate methods to generate appropriate knowledge for practical application.

A quantitative approach was used to answer the first main research question, the impact of the CLWDW Public health interventions, in the form of a three-stage longitudinal (follow-up) survey of people who attended the events, using self-completed questionnaires. Quantitative research was defined by Aliaga and Gunderson [153] as "Explaining phenomena by collecting numerical data that are analysed using mathematically based methods". The approach is particularly useful for measuring the scale and extent of phenomena [154]. This standardised measurement facilitates comparisons; which can be useful for people deciding which



interventions should be applied in different contexts. As the aim of this thesis is to generate knowledge which can be applied in practice, this consideration to decision-making was considered important.

A purely quantitative approach would require that all recorded outcomes of the intervention were pre-conceived. As this was an innovative intervention, this would have been inappropriate, as it was important to capture data on unanticipated outcomes. The questionnaires therefore included some open questions which sought to identify these unanticipated outcomes. This required a semi-qualitative analysis to be undertaken within the quantitative research strand, where findings were summarised by theme, then summarised numerically (but not statistically). This reflects both the pragmatic approach of this thesis, in selecting the most appropriate methodology to answer the question, and the view that there is a valid continuum of methodological approaches, ranging from purely quantitative to purely qualitative.

To answer the second research question, a qualitative approach, in the form of semi-structured interviews, was used to explore people's views and priorities in regards to reducing social distress associated with death, dying and bereavement. A qualitative approach is particularly useful for opening up an area where there is currently little knowledge [155], and in gaining an in-depth and detailed understanding of people's beliefs, experiences, attitudes, behaviour and interactions [156]. This suited the research question which fitted both of these descriptions. As outcomes are not pre-conceived, qualitative research is also best able to address priorities set by the participants rather than the researcher. This was considered important because, as an exploratory study, the priorities of the participants were an important finding in their own right.

The purpose of using mixed methods has been described as 'tapping into different domains of knowing'[157]; and by doing so adding depth or breadth to a study, often facilitating understanding of the processes which are occurring [151]. Mixed methods studies most often have interconnected qualitative and quantitative research questions, such as 'what and how?' [158] and have conclusions that also incorporate both approaches. In this thesis, mixed methods are used to add breadth more than depth. The qualitative research strand, although partially interlinked with the quantitative strand, adding contextual data to help answer the 'how and why?' the intervention had its effects, had the primary objective of opening up the research

area, widening the scope of the research question to include other related needs, priorities and ideas.

Recent thinking also calls for an explicit 'mixed methods' question [146], which could either be an overarching question later broken down into quantitative and qualitative sub-questions (for example, 'where and why?'), or a question on the nature of integration following quantitative and qualitative question (for example, 'how do the qualitative results explain the quantitative results?'). For this thesis there are two overall "mixed methods" questions, both of which related to the integration of the findings.

- "How does the context of the interventions (qualitative) help to explain their effects? (quantitative)"
- "Do the results of the intervention (quantitative) back up the views of the participants interviewed in the qualitative research strand?"

The first question was intended to facilitate inferences as to how transferable similar interventions might be to other settings, and about what can be learned from this intervention which might be applied to others. The second question served as a check on the transferability of the findings of the qualitative research to the wider population they were recruited from, and also facilitated some inferences as the potential effectiveness of other interventions which they suggested might be useful.

### **4.3 Epistemological approach**

Epistemology is the philosophy of knowledge; a set of assumptions about what can be known and about the relationship between the 'knower' and the 'known'. This is not fixed, but can vary according to the nature of the knowledge sought. It is therefore possible to take more than one epistemological approach within a mixed-methods approach. In this thesis, the mixed methods approach has an overall epistemology of its own, while the qualitative and quantitative components also have their own different, underlying epistemologies.

#### **4.3.1 Overall approach**

The mixed methods approach is underpinned by the epistemology of pragmatism. Pragmatism as a philosophy was developed in the USA from the 1870s through to the early twentieth century, but fell out of favour before making a revival in the

1970s [159]. The pragmatic view is that most topics are best understood in terms of their practical applications. It considers that there are many ways to conceptualize the world, and the truth of an idea is not necessarily in its reality, but in whether it is useful to believe and action. The truth of a theory is therefore judged by how accurately it explains a phenomenon. William James, in his 1909 book 'The meaning of truth', described truth as an idea that we can assimilate, validate, corroborate and verify [160]. Pragmatic research has a commitment to outcomes that are useful in practice. Explanations are aimed at understanding our complex reality, and theories are just useful instruments for understanding and prediction. The methodological implication is that research should choose the best methods to answer the questions while being aware of the philosophical debates of the nature of knowledge, as any method has limitations and different approaches are complementary. This seemed applicable to this thesis as the conclusions are intended to directly inform the development of public health interventions and policy. The objective 'truth' of the explanations behind these recommendations is less important than whether the explanations provide useful models in practice.

#### **4.3.2 Quantitative survey**

The conduct, analysis, and interpretation of the longitudinal survey associated with the CLWDW events took a positivist approach. In positivist philosophy, all authentic knowledge, or truth, can be verified using scientific method; systematic observation, measurement, and experiment; usually involving the formulation, testing and refining of hypotheses [161]. Modern positivist philosophy was developed by Auguste Comte in the early 19<sup>th</sup> century. In this context, social science is treated as a continuation of the natural sciences into the realm of human activity, and it is assumed that it can retain the same objectivity and approach to causality [162]. Objectivity is assumed and participants are treated as passive subjects providing measurable data in response to pre-defined questions set by the researcher.

Complete objectivity, which is difficult to achieve even in natural science, is even more difficult, probably impossible, in social science, where humans are both researched and researcher. Findings and their inferences will always be influenced by the researcher and other complex, unknown factors. However, it would not be possible to make sense of the findings of the research without the assumption of objectivity. Therefore, all practical efforts were made to design, undertake and

interpret the findings of the study in such a way as to be objective as possible, and the findings discussed on the context of the methodological limitations of this.

A further methodology, intermediate between qualitative and quantitative, was used within the same survey. Some open questions, with space for short written answers, were included on the questionnaire. This textual data, although not truly quantitative, was summarized numerically and used within the positivist tradition, to confirm and elaborate on responses to other questions.

#### **4.3.3 Qualitative interview study**

The underpinning epistemological approach of the semi-structured interview study was interpretivist. In interpretivist philosophy, there is no one 'truth' which can be objectively verified. Reality as we know it is constructed through meaning and understandings gained through experience and through dialogue with other people. Therefore there are multiple realities in social phenomena, as viewed from different perspectives. When this theory of knowledge is applied to research, this means putting the meaning-making activities of humans at the centre of the research [163]. It is assumed that the researcher and the researched are actively participating in making meaning and generating knowledge together, rather than treating the researched as 'subjects' to be studied objectively. As it is impossible to separate the researcher from what he or she already knows, research is necessarily value-laden. Participants influence the scope and direction of the research, rather than simply provide information in answer to questions set by the researcher. This approach fitted this study particularly well, as the priorities of the participants and wider community were an important part of the research question, not something which the researcher wished to define in advance. This approach also allows relatively natural interaction with the researched, as they are able to truly participate in the research, rather than being passive 'subjects' of it.

### **4.4 Analytical approach**

#### **4.4.1 Quantitative survey**

A mainly deductive approach was taken to the analysis of the quantitative data collected in the longitudinal survey, using statistical methods to test hypotheses. Categorical and numerical data were analysed using standard statistical methods for biological and social sciences, as described in the Methods Chapter 5. Textual

data were used both deductively, as a check on the categorical data collected, and inductively, to describe outcomes and opinions that were not pre-conceived. Textual data was not considered sufficiently 'objective' to be included in the statistical analyses. Instead it was categorised into themes by the researcher and presented numerically by theme.

#### **4.4.2 Qualitative interview study**

An inductive approach was taken to the analysis of the interview data. No theories were tested and no prior assumptions were made, instead, themes and concepts arose from the data. Charmaz recognised that we cannot go blind into research but begin with certain research interests and general concepts [164]. However, there is an ongoing debate within social science as to whether a truly inductive analysis must be undertaken before any literature review, as the findings of the review might influence the analysis. Different approaches to the analysis of qualitative data take different views on this; ranging from the grounded theory approach [165] where every effort is made to ensure that themes arise only from the data, to framework analysis [166] where a thematic framework may be devised before data collection commences. In this study, the literature review was conducted early in the research process to inform the development of the research questions. The researcher had already read comments on the questionnaires used in the other research strand and had had conversations with supervisors and others about the topic of the research. The data used to define concepts was therefore not limited to that obtained through the interviews, but included all of the data gathered during the study, including the literature review, informal observations, and the findings of and observations made during the questionnaire survey. This was consistent with the pragmatic epistemological approach of the thesis, and was also pragmatic in the everyday sense of the word of being practical and realistic.

The method used for the analysis of the qualitative data was thematic analysis, which is essentially independent of theory and epistemology. The result of this theoretical freedom has been described as a 'flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of the data [167]. This method of analysis involves iterative reviewing of the dataset in order to identify patterns within the data which are then analysed and developed by the researcher to form themes [168]. The decision as to whether a pattern is a theme is largely down to the judgement of the researcher, with the most important

consideration being whether or not it captures something important in relation to the research question [167]. Thematic analysis was selected to make maximal use of the broad and varied data that was expected. For example, although participants were asked only about their views and ideas, it was anticipated that many would wish to illustrate these views with examples of their own and other people's experiences. Because this was an exploratory study, aiming to open up the subject area rather than focus on a particular aspect, any pattern which related to the subject area of the research was included as a theme. The intention was to search for both semantic themes (those explicitly described by participants) and, where the data allowed, for latent themes (patterns and explanations underlying semantic themes). In the event, most of the themes presented were semantic themes, as the rich explanations and analyses provided by participants themselves differed very little from the analysis of the researcher.

A disadvantage of thematic analysis is that it can fracture the data, losing some of the meaning in the stories told by individuals by taking themes out of context [166]. Attempts were made to minimise this loss of meaning during the analysis by constant referral back the context of themes within the stories told by the participants, and at the final analysis by including description of context within the description of the findings.

#### **4.4.3 Interpretation of the findings**

The interpretation of the findings was influenced by psychological theories of behaviour change and sociological theories of how social structures and phenomena evolve. This viewed preparing for and talking about death, dying and bereavement as both an individual and a societal issue, influenced by both individual and societal factors. Theories of individual behaviour decisions and of societal influences on behaviour can be considered alongside one another, as they are not mutually exclusive. Theories of individual behaviour recognise social influences, and theories of social life recognise the contribution of individual action.

In regards to individual behaviour change, two theories, or models, were considered; the Theory of Planned Behaviour, and the Transtheoretical, or 'Stages of Change' model.

The Theory of Planned Behaviour, developed by Icek Ajzen in 1985 [169, 170] is generic to any social behaviour or action. According to this theory, a person's

decision to take action, or to behave in a certain way, depends on three factors: attitude towards the behaviour; subjective norms; and perceived behavioural control. Attitude towards the behaviour includes belief in the probability that the behaviour would have a positive outcome and the value given to the performance of the behaviour. This has both rational and emotional aspects to it; for example, attitude towards talking about death might depend both on perception of the likely outcomes and on whether it is felt to 'the right thing to do'. Subjective norms include perception of normative social pressures, and of how their significant others would view the behaviour. Perceived behavioural control is influenced both by level of self-efficacy (how confident they feel in their ability to undertake the desired action) and by external factors which support or hinder the action. In this context, for example, it might include how confident a person feels about discussing end of life issues, combined with the willingness of those around them to discuss the topic. This model can be useful in describing the range of factors which might influence behaviour, helping to identify those which might be targeted by intervention.

The Transtheoretical, or 'Stages of Change' model, developed by James Prochaska from 1977 onwards, is specific to health-related behaviours [171-173]. It was developed to describe changes in regular behaviours which can be difficult to change, such as smoking [174, 175]. The model is therefore only partly applicable to the area under investigation, where the desired behaviour might be a single action, for example, making a will. However, as a description of the thought processes and stages towards changing behaviour (or undertaking a one-off action), it can still be useful. The full model describes six stages, starting with not planning to change behaviour (pre-contemplation) through the stages of contemplation, preparation, action, maintenance, and termination (behaviour change established) [172]. Only the first four stages were considered for this thesis. This was because the concepts of 'maintenance' and 'termination, which relate to sustained change in regular behaviour, are not applicable to a one-off action. At the pre-contemplation stage, a person is not intending to change their behaviour. They may be unaware of the potential benefits of changing, or perceive that the benefits are outweighed by the costs. At the contemplation stage, they are more aware of the benefits, but are ambivalent about changing, as these seem to be equally balanced by the costs. At the preparation stage, the person perceives the benefits to outweigh the costs, and starts to prepare themselves to make the change, and perhaps talks with others about this. The action stage is where they make the change. The core of the model is decisional balance [172], a person's evaluation of

the benefits and costs, which changes between the pre-contemplation and preparation stages towards favouring change. Once the balance of the decision seems in favour of the change, self-efficacy [176] (the perceived ability to perform the task) influences whether the person feels able to make the change.

In this model, movement between different stages is influenced by different external and internal factors. Movement from the pre-contemplation towards the preparation stage might be influenced by consciousness-raising (increased awareness of the benefits of the healthy behaviour); environmental realisation (realising how their unhealthy behaviour affects others); social liberation (realising that society is more supportive of the healthy behaviour); or dramatic relief (of worry caused by the unhealthy behaviour). Movement from the contemplation to the preparation stages might be influenced by self-re-evaluation (seeing the healthy behaviour as an important part of who they want to be). Movement from preparation to action might be influenced by self-liberation (believing in one's ability to change and making a commitment to act on this) and helping relationships (finding people who are supportive of the change). The model describes not only the factors that might be need to be considered when designing interventions to facilitate behaviour change, but also how these different factors might apply to different people or at different stages in a campaign.

The commonalities of the two models are that behaviour change or action is most likely when a person perceives the benefits of action outweigh perceived costs or risks; when a person feels confident in their ability to perform the action, and where they have the support, or perceive they will have the support, of people around them.

The underpinning sociological theory (theory of how society and social life work) used to draw inferences was the 'Theory of Structuration', described by Anthony Giddens [177]. This theory unifies social action (interpretivist) theories and functional (positivist) theories, and assumes that both factors are present and influence social life. This has been termed the 'duality of structure'. Social action theories, such as symbolic interactionism, assume that society is a result of the constant social interaction of people, and human action is the result of individual's thinking. Within social action models, a person's decision to talk or not to talk about death would be made according to their own conscious thought and interactions with other people. Functional theories suggest that individual human actions are guided by societal consensus to serve specific functions in society. These functions



then generate structures which uphold the consensus. Within functional models, an individual decision to talk or not to talk about death would be the result of a general consensus of what is 'the done thing'. That consensus serves a purpose in society that the individual may not be consciously aware of, or has served such a purpose in the past.

Giddens stated that "Human agents are constantly intervening in the world by their actions and in doing so they have the capacity to transform it. However, structural factors affect human behaviour because of the knowledge that agents have about their own society. There is a large stock of mutual knowledge and 'how to go on'". This suggests the existence of mutual knowledge or tradition which tends to produce regulations in social life (which may include talking or not talking about death in different situations), but there is always the possibility that society can be changed. As individuals also act in response to their own thinking, they may choose to ignore or go against any assumed consensus. If enough people did this, this might eventually change the underlying consensus.

This broad theory provides an optimistic framework on which to base any recommendations for future actions at societal level, as it describes how any structural barriers to positive behaviour might eventually be removed. According to this theory, any structural barriers to talking about death which might exist are based on mutual knowledge, which serves a function, or has served a function in the past. Where these barriers serve useful functions, they need to be respected and taken into account. Where structural barriers are unhelpful, they can be overcome via a change in the conscious thinking process and personal interactions of individual members of society, resulting in an eventual change in the mutual knowledge base, and a reduction in structural barriers.

## **4.5 Ethics**

Any research which causes people to consider issues of death and bereavement needs to be conducted in a sensitive fashion in order to minimise the risk of causing distress to the participants. This study met this responsibility in three ways:

- *Consent:* All participants were over the age of 18, had capacity to consent and were not known to be vulnerable in any way. Sufficient information was provided to allow participants to make an informed decision on whether or not to participate. All possible efforts were made to ensure that no person

felt pressurised to take part in or to continue in the study if they did not want to.

- *Control by the participant:* Questionnaires were self-completed, so respondents could easily choose not to complete any questions which may have caused them discomfort or distress. Interviews were held following a positive response to an invitation to participate, and at a time and location of the interviewee's choice. Participants were not asked about potentially sensitive subjects such as personal bereavements, end of life wishes or feelings about their own mortality. In the event, every participant chose to talk about at least one of these issues.
- *Supportive settings and sensitive attitude:* Baseline questionnaires were completed at events where a trained facilitator and often also trained CLWDW volunteers were available to talk about any issues which might arise from the questionnaire. Interview study participants were informed before the interview that they could stop or have a break at any time if they wished. Questions were asked sensitively and care was taken not to probe for more information than a participant was comfortable with. Where participants became emotional during an interview, the researcher asked whether they would like to take a break for a while.

In practice, there were no reports of anybody being uncomfortable or distressed by the questionnaire; although it did generate a few discussions, most often on the topic of wills. Three participants became slightly tearful during the interview; all three chose to continue with the interview and assured the researcher that they had not experienced any distress. One participant commented that being able to cry was a positive thing.

## **5. Methods**

### **5.1 Study population**

The study population comprised people who attended two different types of CLWDW public health event during the 12-month period between the start of April 2013 and end of April 2014. During this period, there were 64 events. Respondents were recruited at 61 of these events, including 40 'Awareness Raising' presentations and 21 'How To' workshops; attended altogether by a total of 676 people.

Three events held during the period were not included in the study. At two events, there was insufficient time to incorporate the survey. At another event, the facilitator decided not to use the questionnaire because she was aware that two of the people attending had learning disabilities and did not want to risk drawing attention to that.

The sampling procedure for the quantitative survey was 'census' sampling. As far as possible, all members of the study population who expressed their willingness to participate were included. This sampling method was used to maximise the sample size and minimise recruitment bias.

The sampling procedure for the semi-structured interview study was a pragmatic combination of 'convenience' sampling and 'purposive' sampling. The intention was to recruit up to 30 participants, of a range of different ages and including a balance of males and females, unless data saturation (the point at which no new themes seemed to be emerging) was reached earlier. For convenience and efficiency, only people who returned a 'Follow-up' questionnaire (see Section 5.3 research Tools) were invited, as they had already provided their contact details and permission contact them, and had already shown an interest in the study. At the beginning of the recruitment period, all eligible persons were invited. Later in the recruitment phase, it became clear that there was sufficient interest in the project and that there was an imbalance in the sample between the numbers of males and females. The sampling procedure then became more purposive, in that invitations were sent only to males. The sampling and recruitment procedure is described more fully in section 5.5.2.

## 5.2. Interventions

The Cheshire Living Well Dying Well Partnership delivered two different types of public health event to the public; Awareness-raising presentations and 'How to' workshops. All were delivered by a CLWDW End of Life Public Health Worker, usually supported by trained volunteers or other CLWDWP staff members.

### 5.2.1 Awareness-raising presentations

Awareness-raising presentations aimed to raise awareness among attendees of the benefits of planning for the future, including end of life and death, and talking openly about death, dying and loss. They also aimed to introduce the Cheshire Living Well Dying Well Partnership and the idea of compassionate communities, and give some ideas of where to start and where to find further information. The events were targeted and delivered mainly to community groups, generally using a 'visiting speaker' slot. They were also delivered to interested members of the public, via open invitations; and to people working in health and social care, re-packed as training in 'Making the Professional Personal'. This presentation was basically the same as those delivered to other groups, but with a slightly different introduction. In all cases, the presentations were delivered free of charge.

All presentations were scheduled to last between 60 and 90 minutes, the most frequent timing being 75 minutes for the presentation plus an extra 15 minutes for questions and viewing of resources. Presentations had an interactive and varied format, designed to suit a range of learning styles. The content and delivery varied slightly between presentations to suit the needs of the group, time available and factors such as group size and room set-up.

Most presentations started with a group discussion about *"What was life like when the last London Olympics were on in 1948? How has life changed?"*. The facilitator then used the results to discuss how changes to society mean that people now, compared with those in 1948, may have less direct experience of death, and less support from people around them if they are ill, caring for somebody or bereaved.

This was followed by showing a short film, 'Cheshire Bill United', locally adapted from the original 'Bill's Story' produced at The Milford Care Centre in Ireland [178], which used drawings and captions to tell the story of a community coming together to support Bill and his family as he is diagnosed with a terminal illness, becomes ill

and eventually dies. After the film, the audience was asked for their reactions and the concept of a compassionate community was briefly introduced and described.

Following 'Cheshire Bill United', the presenter spoke about some of the benefits of planning for the future and of talking about death, dying and loss, using PowerPoint slides as visual aids, making it interactive by asking questions of the audience and encouraging contributions. This was followed by a very short presentation of the aims of the Cheshire Living Well Dying Well Partnership, leading immediately into an animated montage on the theme of the 'Circle of Life', produced by the CLWDW Programme Lead, which made the point that death was inevitable but could be made easier, especially for the people left behind. The Circle of Life presentation had no dialogue but was accompanied by a local brass band recording of the tune, 'Circle of Life', from the film, 'The Lion King'.

The presentation ended with another short film, 'Dying for a Laugh', produced by the National Dying Matters Coalition [179] and adapted for use by the CLWDW Programme Team, which comprised clips of famous comedians talking and making jokes about death. After the film, the presenter made attendees aware of leaflets and other resources available on a stand in the room, and remained to answer questions and talk to individuals for up to 30 minutes as needed.

### **5.2.2 'How to' workshops**

'How to' workshops aimed to increase participants' confidence and equip them with some useful tools to facilitate conversations about end of life plans or wishes with people close to them. Specifically they aimed to provide awareness and understanding of the potential barriers to talking to family about dying and end of life wishes, an understanding of basic good communication skills, and examples of how to apply those communication skills to end of life discussions. The workshops were advertised under the name 'Dying to Talk' through the Awareness-raising presentations and directly to groups, including carers' support groups. They were also re-packaged as 'How to: Making the professional personal' for people working in health and social care, provided during the working day as part of their professional and personal development. In all cases, the workshops were delivered free of charge.

All the workshops followed a similar plan, with each lasting between 150 and 180 minutes. Most workshops used two facilitators. All began with an ice-breaker followed by a group discussion about the participants' 'hopes and fears' for the

workshop, using a flip chart to make notes. The first facilitator then lead a discussion about the benefits of talking about end of life wishes, for the individual and family; followed by another discussion (in small groups if numbers were sufficient) about what holds people back. The second facilitator then spoke to the group about things that might help, using symbols on laminated cards as visual aids. These included:

- talking upstream (discussing end of life when it still seems a long way off)
- planning (planning what to say)
- practice (practicing what to say)
- triggers (finding a suitable trigger for the conversation, such as a storyline in a soap opera)
- listening (listening carefully to what the other person is saying)
- starting (starting by telling the other person your own end of life wishes)

After a refreshment break, depending on the time available, either one or two videos of role-play scenarios were shown. Scenario 1 showed a wife who wanted to talk to her husband about his wishes. Scenario 2 showed a daughter who wanted to talk to her mother about her mother's wishes. In each scenario, one person wanted to discuss the other's end of life wishes, while the other was reluctant to talk. Each scenario included first an example of 'poor communication' and then an example of 'good communication'. The videos were produced by the CLWDW Public Health programme using the workshop facilitators as actors.

After the viewing the example of 'poor communication', participants were asked to give feedback as to what went wrong and what could have been done differently to achieve a more positive outcome. After the example of 'good communication' the group were asked to give feedback about what worked better that time. During the review of the scenarios, the second facilitator highlighted some of the barriers and some of the good communication skills that were used, using the laminated picture cards and PowerPoint slides. This was followed by a short summary of the learning and observations from this part of the workshop.

The first facilitator then gave a 15 minute presentation giving practical information, facts, and ideas relating to: wills, power of attorney, advance care planning, funeral plans, letters of wishes, emotional wills and bucket lists.

The workshop ended with an opportunity for participants to ask questions, an evaluation of the session, and handing out of information packs to participants.

### 5.3 Research tools

The quantitative survey used three different questionnaires at three different time points:

- 'Baseline', immediately before an event;
- 'Post', immediately after the event; and
- 'Follow-up', three months after the event.

Each questionnaire was printed with a unique study number which was used to link 'Baseline and 'Post' questionnaire data with 'Follow-up' data for the same individual. The 'Baseline' questionnaire also included a cover sheet with information about the purpose of the study, the funding source and how the data would be used.

The 'Baseline' and 'Post' questionnaires were presented together as one document. The 'Baseline' questionnaire, intended for completion immediate before events, comprised mainly forced response questions. It included questions about demographic details; wills and intentions to write or update a will; questions experience of talking with close friends and family about end of life wishes and comforting people who have been bereaved; and about how comfortable (on a scale of 1 to 10) respondents felt about talking about these subjects. Some of the questions were purposely similar to questions included in the Dying Matters 2012 survey [7], to allow comparison with a representative national sample. At the end of the Baseline questionnaire, there was a page break with instructions not to go any further until after the event had finished.

The 'Post' questionnaire, intended for completion immediately after events, followed a page divider and blank page. It comprised questions about the respondent's perception of the event and any intentions they had for specific conversations or other actions because of the event. There were both forced answer questions and space for free text responses. The question about wills was repeated exactly from the 'Baseline' questionnaire. The questionnaire ended with a request for permission for the researcher to contact the respondent about further research, and for their contact details, including telephone, email and full address.

The 'Follow-up' questionnaire, a separate document intended for completion three months after events, repeated the questions from baseline about experience of and how comfortable respondents felt talking to close friends and family about end of life wishes and comforting people who are bereaved. It also repeated questions from

the 'Post' questionnaire about the relevance to the respondent of the event, and asked about action taken and changes made as a result of attending the event, including a specific question about talking to close friends and family about their own end of life wishes.

Copies of the questionnaires can be found in Appendix 2.

A semi-structured topic guide was used to start discussions and guide the topic areas covered in the interviews. Open questions were used to enable participants to answer in their own way and encourage lengthy, detailed answers. Care was taken to ensure that the questions were not 'leading' so that participants would not be influenced by what they thought the researcher might want them to say. Prompts were used where necessary to clarify or elaborate on questions. In practice, questions sometimes had to be clarified, but most participants talked at length without the need for prompting. The guide was used with flexibility; where a participant wished to talk about the included topics in a different order to the topic guide, or to talk about something slightly off-topic, they were allowed to continue. If they had misunderstood the question they were allowed to continue their response, and when they had finished were asked the original question again in a different way.

All interviews began with an invitation to talk a little about themselves. This was done to obtain contextual data for the rest of the interview. It also helped start the flow of discussion and build rapport between the researcher and participant, which is known to be important to elicit good quality data [180]. Further questions asked about perceived importance of discussing end of life wishes with family and friends, perceived ability of people in general to support others who are dying, caring for somebody who is dying, or bereaved, and any ideas they had for actions to help improve the situation. Every interview ended with an invitation to talk about anything else they thought was relevant to the topic. This was to add flexibility into the interview schedule so that participants might talk about issues that were important to them but had not arisen during the course of the interview. It also helped to end the interview in a natural and positive way.

The topic guide evolved slightly during the course of the fieldwork. After the first five interviews, a further question was added, regarding how the person had come to attend a CLDWD event. This was intended to add some context as to their interest in the subject area and how they came to be included in the study, and also helped with building of rapport and natural interaction. Questions regarding support for



people who were dying or caring for somebody who was dying, and people who were bereaved, which were separate on the original topic guide, became combined in many interviews as participants chose to discuss them together. Because this happened naturally, towards the end of the fieldwork period these questions were usually combined into one by the researcher.

A copy of the interview topic guide can be found in Appendix 3.

Throughout the research process the researcher also kept a reflective diary to document the process of developing ideas in association with the data as it emerged, as well conversations with the researcher supervisors and advisors, CLWDW team members, and other influences, such as current news items. This provided a valuable resource for the interpretation of the findings and writing up of the thesis.

## **5.4 Development and Piloting**

The questionnaires for the longitudinal survey were designed by the researcher in consultation with the research supervisors, the project advisor and the CLWDW public health worker. Late drafts of the 'Baseline' and 'Post' questionnaires were piloted at a pilot CLWDW awareness-raising event attended by nine people, mainly CLWDW programme volunteers. Attendees were invited to comment on the questionnaire by writing on the questionnaire itself, speaking at a group discussion immediately following the event, and by email or telephone afterwards. The public health worker also contributed at this stage, commenting on the length of the questionnaire and how it might best fit into the events. Following the pilot, some minor changes were made to the content and presentation of all three questionnaires. Piloting of the 'Follow-up' questionnaire was not considered necessary because it comprised mainly of questions repeated from the 'Baseline' and 'Post' questionnaires

The topic guides for the in-depth interviews were designed by the researcher in consultation with the research supervisors and the project advisor. An early draft was piloted with a supervisor as the interviewee, and changes were made to make the flow of questions more natural. A later draft was piloted using a friend as the interviewee, after which the topic guide was adopted unchanged. Further piloting was not required as the qualitative method used enabled changes to be made to the topic guide during the conduct of the research.

## **5.5 Recruitment and data collection**

### **5.5.1 Quantitative Survey**

The 'Baseline' and 'Post' questionnaires were administered by the public health worker at CLWDW Awareness-raising presentations and 'How to' workshops. At some of the larger events, the public health worker was assisted by CLWDW volunteers. To observe how the events and survey were working in practice, the researcher attended and assisted at three Awareness-raising events and one 'How to' workshop. As far as possible, all attendees were approached and asked to complete a questionnaire. Assistance with the questionnaire was provided where requested or where individuals were observed to be having difficulties, for example, due to poor vision or difficulty writing. A small number of attendees may have been missed, for example if they arrived late, but no records were kept of this. Clipboards and pens were provided to everybody who took a questionnaire. Attendees were requested to complete only one questionnaire, even if they attended more than one event; for example if they attended a 'How to' event as a follow-up to the awareness-raising event. This was checked at the analysis stage by checking for possible duplicates, based on person details of age group, sex and postcode. There was no evidence of any individual entering the survey more than once.

At the start of the recruitment period, the survey was introduced and questionnaires given out after the topic of the event had been introduced, and time was allowed within the event for attendees to complete the questionnaires. This was due to initial concerns that the topic of the questionnaire would 'put people off' if it was given prior to events. However, the public health worker observed that no attendees seemed to be made uncomfortable or distressed by the questionnaires, and that including introducing the questionnaire seemed to disrupt the flow of the events. Therefore, from July 2013, questionnaires were given to individuals as they arrived at events, and they were asked to complete the Baseline section of the questionnaire before the events began. This did not appear either to cause any distress or disrupt the flow of events.

At the end of each event, the public health worker gathered the completed questionnaires and returned them to the researcher with details of the associated event; including type of event, target group, date, location, and number of people attending.

Where respondents had given permission to be contacted and provided a valid postal address, a copy of the 'Follow-up' questionnaire was sent to them by second class post, as close as possible to four days before the three-month follow-up date. Where participants provided permission, but did not provide a valid postal address, attempts were made to contact them by email or telephone to request details. To maximise response rates, a pre-paid return envelope was included, and the researcher added a hand-written 'thank you' message to the front of the questionnaire. Where questionnaires were not returned within two weeks of posting, one reminder was sent, in the form of a second questionnaire, again sent by post.

### **5.5.2 Qualitative Interview Study**

Recruitment to the interview study was conducted in two phases. From June 2013 to May 2014, approximately once a fortnight, invitations to participate were sent to respondents of the 'Follow-up' questionnaire survey who had not been contacted before, and reminders were sent to everybody who had been invited once but had not responded. In this phase, all persons who contacted the researcher and wanted to participate were recruited. After February 2014, reminders were no longer used, as there had been an adequate response rate from first invitations alone. During June and July 2014, invitations were sent to men only, to boost their numbers in the study sample, which at the time was dominated by women. Recruitment was stopped in July 2014 after the target number of participants had been recruited. At this stage, no further invitations were sent and people who expressed an interest as a result of invitations already sent out were not recruited, although they were offered feedback of the study's results, which all three accepted.

Invitations were sent by post, and where possible, also by email. A participant information leaflet was enclosed/ attached with the invitation (Appendix 4). Participants were asked to contact the researcher by telephone or email if they wanted to discuss the study further or to arrange a time and place to meet. The majority of first contacts by participants were made by email. In most cases, the researcher followed up initial emails with a telephone call. Where no telephone number was available or where the participant was difficult to contact, email was also used to arrange a time and place to meet. The most common question asked by participants at this stage was how long the interview would take. It was suggested that it might take around 30 minutes to an hour, but that the participants was in control and it would depend on how long they wanted to talk for. At the beginning of the recruitment period, attempts were also made to follow the written

invitations with telephone calls. This was discontinued because there was an adequate response rate to the written invitations alone.

Participants talked about a wide range of experiences and therefore there was no point where complete saturation of themes seemed to have been reached.

Interviews continued until the planned maximum sample size had been reached.

Three participants asked to include another person in the interview; in two cases a husband or wife, and in the other case a friend and business partner. In both cases the additional person also met the study inclusion criteria and in both cases this request was granted and the two participants were interviewed together. A total of 31 participants were included in 28 interviews.

Interviews were conducted at a time and venue preferred by the interviewee, for their convenience, and to help them feel at ease and in control of the interview. The majority (23 participants) arranged to be interviewed in their own home, five preferred to meet in an office or meeting room at their workplace, two were interviewed in a café at their workplace, and one was interviewed at a coffee shop near her home. All venues seemed equally suitable and productive in terms of data collection. However, background noise made the interviews conducted in cafes more difficult to transcribe, and some small details may have been lost from these interviews.

Participants were informed that, although the researcher would be asking only about their views, and not about personal experiences, she recognised that death could be emotional subject for some people if at any time they wished to take a break or stop the interview this would be fine. In the event, although most participants chose to discuss deaths that were personal to them, most did not appear to become emotional and none required support or chose at any time to take a break.

All interviews were audio recorded using a digital recorder (Olympus model DS-40), which was discrete in appearance and did not need to be placed very close to the speakers. Thus self-conscious awareness of the recording was minimised allowing interviews to be conducted as naturally and comfortably as possible.

Interviews lasted on average for about 45 minutes, although this varied widely, between 20 minutes and just over two hours. Following the interviews the participants were asked whether they would like to ask any questions. Many asked about how the findings of the research would be used, and this was discussed. Participants were then thanked and asked whether they would like to receive a copy

of the interview transcript or summary of the discussion to check and give further feedback. All but one participant declined this offer. The one participant who asked for a transcript did not provide any feedback. Participants were also offered a summary of the main findings of the study at the end of the project. All participants accepted this offer.

After each interview field notes were compiled that combined the researcher's observations about the setting and context; developing ideas about possible interpretations; and personal notes about the interview itself and the informant in particular, including reflections regarding relationships. Also noted were relevant conversations with the participants that occurred after the end of the interviews, as were pertinent conversations with other people that occurred during the course of the study.

## **5.6 Consent**

Consent for participation and use of questionnaire data was not formally recorded. This approach was taken to minimise the complexity and time taken to complete the questionnaires, and was considered justifiable by the low burden and low risk to the participants. Clear information on the purpose and use of the data was provided on the front of the questionnaire, and the public health worker or researcher was available to answer any questions about the research. There was no pressure put on people to participate. All participants had apparently willingly completed a questionnaire and given it to the event facilitator or researcher. In the case of the follow-up questionnaire, participants also provided their explicit consent to be contacted, and had provided contact information including their name and address.

Written consent was taken from people participating in the research interviews. This included a check that the participant had read the relevant information leaflet, was aware that they were free to withdraw from the study at any time, were entitled to see or request the destruction of any information they provided, agreed that the interview would be audio-recorded and agree to the information being used in anonymous form in publications, conference presentations or other similar events. The participants kept one copy of the consent form and the researcher filed the other copy in a secure place. A copy of the consent form is included in Appendix 5.

## **5.7 Data handling**

### **5.7.1 Questionnaires**

All questionnaire data was entered by the researcher into an electronic database (Microsoft Access 2007), using an electronic data entry form with appropriate validation checks. To improve accuracy, the full record for each questionnaire was re-checked once, on a separate occasion from the initial data entry. Each CLWDW public health event and each person included was allocated a unique code for data linkage. Event codes were allocated at data entry. Individual codes, in the form of sequential numbers, were pre-allocated to the baseline and follow-up questionnaires at the printing stage.

After all data entry and checking was completed, an indicator of relative socio-economic deprivation was added to the dataset. Lookup tables were downloaded from the UK Office for National Statistics website [181] and Department for Communities and Local Government [182] as Excel spreadsheets and imported into the database. Using these Lookup tables, queries were run to link the postcodes of individual respondents to Census 2011 lower level super output area (LSOA) and LSOA to rank of deprivation within England, according to the 2010 English Index of Multiple Deprivation (IMD 2010). These provide the most accurate measure of deprivation by geographical area. This linkage process excluded records for the minority of respondents who did not provide a valid postcode or who lived in Wales.

The full dataset was exported first into a spreadsheet (Microsoft Excel 2007) and then from Excel into the statistical analysis packages SPSS Statistics 2. The analysis was undertaken from the original dataset using all three of these packages where appropriate.

### **5.7.2 Interviews**

Recorded interviews were transcribed by the researcher as soon as possible after they were conducted. This was done to ensure that transcripts reflected the interview as accurately as possible and was also part of the process of familiarisation with the data; the first stage in analysis process. A transcription protocol was used to ensure consistency and increase the dependability of the data. To ensure that as many features of speech were captured as possible, the following protocol was used:

- Interviewer identified as K
- Participant identified as P, except where there were two participants, in which case they were identified by their pseudonyms
- Break offs (i.e. when someone starts to articulate an idea and stops midstream) were marked with “—”
- Non-lexical expressions such as “uhm” and “uh huh” and discourse markers like “y’ know” were left in the transcripts
- Paralinguistics such as ‘laughs’; extralinguistics such as ‘phone rings’; and prosodics such as whispers, were recorded in brackets
- Short hesitations were recorded as (..), longer hesitations were recorded as (...).
- Double quotation marks were used for reported conversations

For anonymity, each participant was given a pseudonym. The pseudonyms selected were names that are relatively common to people of the same age and gender as the participant. To maintain the anonymity of data presented in quotes, the names of any people mentioned by the participants were also changed to an appropriate pseudonym.

To add reliability to the data all transcripts were read by Mari Lloyd-Williams, and a random selection of transcripts were also read by Paula Byrne and Siobhan Horton and all key themes and subthemes were agreed by the supervisory team. All transcripts were imported into Nvivo software which was used to aid the analysis.

## **5.8 Data security**

Completed questionnaires and consent forms were handled only by the researcher and stored in a locked drawer in a secure office at the University of Liverpool.

Electronic data, including audio files, were stored on a password-protected secure network drive at the University, accessible only to the researcher. Care was taken in the presentation of results to ensure that, as far as possible, no individuals could be identified. However, this could not be absolutely guaranteed because many were associated through their work or volunteering with the hospice or CLWDW programme and already knew each other and their stories. These participants were aware of this and did not appear to be concerned about it.

## 5.9 Analysis

### 5.9.1 Quantitative survey

Two main analyses were conducted of the questionnaire data obtained through the longitudinal survey. The first included the respondents to the 'Baseline' and 'Post' questionnaires, and was limited to these two questionnaires. The second included only those who had also returned 'Follow-up' questionnaires and included linked data from all three questionnaires.

- *First Analysis: 'Baseline' and 'Post' questionnaires only*

Respondents' self-reported characteristics were summarized using descriptive statistics. Sub-group analyses were undertaken to identify any associations between experiences of talking to close friends and family about end of life wishes, how comfortable respondents said they felt about having those conversations, preparation for death in the form of a will, and other personal and demographic factors.

Respondents' ratings of the relevance of the event, and whether or not they planned any action as a result of attending it, were summarized using descriptive statistics. Sub-group analyses were undertaken to identify any associations between these responses to the event and demographic and personal factors. Free-text data was summarized thematically; raw numbers were presented, but no other statistics were used.

- *Second analysis: 'Follow-up'*

To identify and describe any response bias, comparative analyses were undertaken between responders and non-responders to the follow-up survey. Questions which repeated from previous questionnaires, relating to wills, previous conversations about death-related topics, and how comfortable people were about having these conversations, were compared statistically to assess changes between the baseline and follow-up points. Responses related to responses in previous questionnaires, for example, whether any action was intended immediately after the event and whether any action was reported at follow-up, were also compared statistically. Free-text data was summarized using the same methods as for the 'Post' questionnaire, and attempts were made to compare the themes of these responses immediately after the events and at follow-up.



- *Statistical Methods*

Ratings scores were treated as continuous data. Means and 95% confidence intervals were computed. An independent samples t-test was used for comparing group mean scores. A related samples t-test was used for comparing mean scores before and after the intervention. The Friedman's test was used for comparing scores of multiple items for the same group of respondents.

For categorical data, a chi-squared test and a chi-squared 'test for trend' were used for comparing proportions of groups of respondents. An exact test for paired data was used for comparing proportions before and after the intervention.

Two-sided significance tests were used, except where change in scores or proportions could only take place in one direction.

Where appropriate, logistic regression models were constructed and run in order to measure the independent effects of respondent variables on binary outcomes. For the covariate of interest, Odds Ratio and 95% CI were presented.

For all tests, a conventional criterion of statistical significance ( $P < 0.05$ ) was used.

### **5.9.2 Qualitative Interviews**

The transcription and preliminary analysis was an ongoing process undertaken during the fieldwork phase of the study, and the ongoing emergence of candidate themes informed the direction of inquiry in interviews which followed. After transcribing the data, the researcher further familiarised herself with the data by listening to each interview, reading each transcript several times, and making notes in the reflective diary. This familiarisation process was intended to help avoid loss of meaning associated with the process of identifying discrete themes within the overall narratives. After this initial familiarisation with the data, coding of the data was started in Nvivo. The purpose of this was to provide a means by which data extracts judged to be related to a particular heading or topic can be retrieved with ease, and the volume of data under each heading kept manageable and meaningful [183].

Following the initial familiarisation, the coding and analysis was undertaken in four stages, although the process was not linear and there was some going backwards and forwards through the stages. In the first stage, pieces of data which appeared to

have a recurring pattern and were relevant to the research questions were identified and first assigned preliminary codes. Notes were made, within the software, on the meanings of these codes. As new transcripts were added and the dataset became larger, codes were reviewed or split, and new codes were added. Coding was kept open and included all of the relevant data, so as not to discard any data which might later be useful to the analysis.

In the second stage, the researcher began searching for themes within the data. Codes were reviewed and combined into candidate themes that reflected the data as accurately as possible. This process involved a search for connections between different codes. The researcher tried to remain mindful of the context of the pieces of text supporting each code. At this stage, a selection of the transcripts and their corresponding emerging themes were reviewed and discussed between the researcher, supervisors and external advisor. This acted as a check on the consistency of the data to the candidate themes and also helped with the interpretation of the data and the further refinement of themes that comprised the final stage of the analysis.

In the third stage, the candidate themes were reviewed, combined and split in terms of how they supported the data, resulting in the final themes for analysis.

The final stage was an analysis of how the different themes contributed to an overall understanding of the data; or how they fit together. This final stage guided the structure of the Findings Chapter 8.

The findings are presented in the conventional way. Each theme is introduced and briefly described. Within each theme sit the sub-themes, which are illustrated with direct quotations from the interview transcripts. The quotations demonstrate that the analysis is backed up by data, and can add depth and understanding to the themes [184]. Quotations were 'cleaned' for ease of reading, for example repetition of "mmm" or "you know", or superfluous details. These words and sounds have been removed, this is represented by "....". Quotations were selected for inclusion based on how well they captured the essence of the construct it was describing.

## **5.10 Ethical Approval**

The application to proceed with the study was submitted to the University of Liverpool Research Ethics Non-Invasive Sub-Committee in October 2012 and formal approval was given in the same month (ref: RETH000583, see Appendix 5).

### **5.11 Deviations from the original protocol**

The protocol submitted to the ethics committee included an additional strand of work to conduct focus groups with members of staff and volunteers of the CLWDW Public Health project and with people who work in professions caring for people with life limiting illnesses. This was dropped as it became apparent that members of both these groups were keen also to contribute their personal, non-work experiences to the research, and that other people, not formally identified as belonging to one of these groups, also had experience of working with or volunteering with people who were dying. Thus CLWDW volunteers, people working in health and social care, and other people not within either of these categories were deemed to comprise the same population and were included together in the semi-structured interview study.

Plans to use telephone reminders for people who were sent follow-up questionnaires were also dropped, due at first to lack of resources and then to the high response rate (70%) to the follow-up questionnaire survey using only postal reminders where necessary. A contingency plan to advertise for additional participants for the interview study was not implemented as sufficient numbers were recruited from the population of people who returned 'Follow-up' questionnaires.

## **6. Questionnaire survey: Results**

This section is divided into two main sub-sections. The first presents the findings of the 'baseline' and 'post' surveys, using data provided by all of the survey respondents. The second presents the 'follow-up' survey results, including changes from baseline and immediately post-event, using data only from respondents who completed and returned 'follow-up' questionnaires.

### **6.1 Baseline Survey: Questionnaires completed immediately before CLWLDW events**

#### **6.1.1 Number and type of events**

During the 63 week period 04/02/2013 to 23/04/2014, there were 64 CLWLDW events. Respondents were recruited at 61 of these events, including 40 'Awareness Raising' presentations and 21 'How To' workshops. Forty-seven events were delivered to community groups, seven were openly advertised, and seven were provided specifically for health and social care professionals.

The number of people attending each event ranged from two to 34 (median 9, mean 11). The total number of people attending the events where questionnaires were used was 676.

#### **6.1.2 Response rate**

Of the 676 attendees, 503 (74%) completed at least some of the questionnaire; and 498 (still 74%) were included in the analysis as they provided at least some demographic data and some additional data. Of these, 478 (71%) also completed a questionnaire immediately after the event, and 214 (32%) gave permission for further follow-up.

Response rates were higher at 'How to' workshops compared with 'Awareness Raising' presentations (69% v 84%) and at events aimed at health and social care professionals (95%) compared with events openly advertised to all (87%) and events for community groups (70%). Response rates for individual events ranged from 9% (1 of 11) to 100% (15 of 15).

The number of events, number of people attending the events and number of people completing usable questionnaires are summarized by type of event in Table 4.

**Table 4: Number of CLWDW Public Health events covered by the questionnaire survey, number of people attending and response rate by category of event**

	'Awareness-raising'			'How To'			Totals		
	No. Events	No. People Attending	No. People Responding	No. Events	No. People Attending	No. People Attending	No. Events	No. People Attending	No. People Responding
Community Group	37	438	295 (67%)	10	120	96 (80%)	47	558	391 (70%)
Openly Advertised	2	25	22 (88%)	5	36	31 (86%)	7	61	53 (87%)
Professional Group	1	9	9 (100%)	6	48	45 (94%)	7	57	54 (95%)
<b>Totals</b>	<b>40</b>	<b>472</b>	<b>326 (69%)</b>	<b>21</b>	<b>204</b>	<b>172 (84%)</b>	<b>61</b>	<b>676</b>	<b>498 (74%)</b>

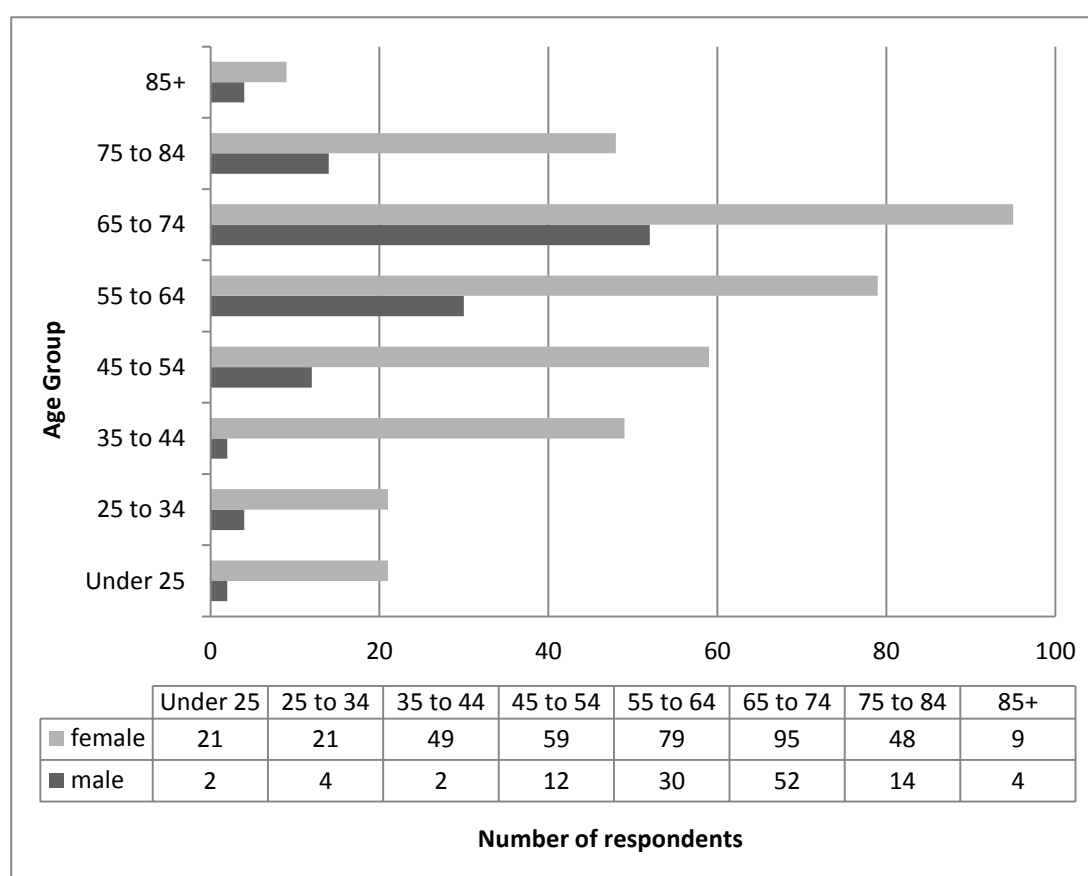
**Table 5: Number of respondents to baseline questionnaire survey by age group, sex and category of event**

		Awareness Male	Awareness Female	How to Male	How to Female	Awareness Total	How to Total	Male Total	Female Total	Total
Age Group	Under 25	0	5	2	16	5	18	2	21	23
	25 to 34	1	10	3	11	11	14	4	21	25
	35 to 44	1	31	1	18	32	19	2	49	51
	45 to 54	6	33	6	26	39	32	12	59	71
	55 to 64	23	42	7	33	65	40	30	75	105
	65 to 74	33	75	19	20	108	39	52	95	147
	75 to 84	10	43	4	5	53	9	14	48	62
	85+	3	9	1	0	12	1	4	9	13
	<b>Total</b>	<b>77</b>	<b>248</b>	<b>43</b>	<b>129</b>	<b>325</b>	<b>172</b>	<b>120</b>	<b>377</b>	<b>497</b>

### 6.1.3 Demographics

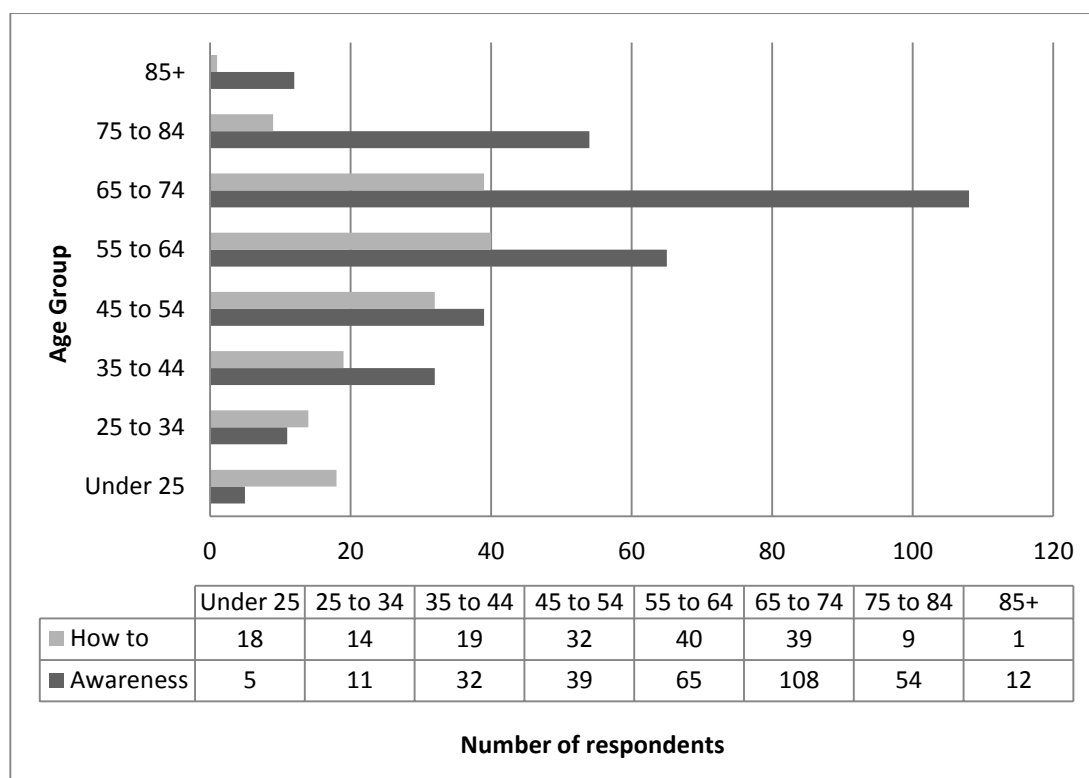
#### Age and Sex

The survey sample included 377 (76%) females and 120 (24%) males. 'Awareness Raising' and 'How to' events had similar proportions of females (76% v 75%). Ages were recorded in eight bands; under 25, 85 and over, and six 10-year age bands in between. Every age group was represented. The majority of respondents (252, 51%) were aged between 55 and 74, with the largest age group being 65 to 74. Just under half (222, 45%) were aged over 65. Male respondents were on average older than the females; 58% of the males (n=70) were over 65 compared with 40% of the females (n=152). Figure 3 shows the number of respondents in each age group by age and sex, for all events combined.



**Figure 3: Number of respondents to the baseline questionnaire survey by age group and sex**

Respondents attending 'How to' events were younger on average (29% over 65) than those attending 'Awareness' events (54% over 65). The age group with the largest number of respondents was 65 to 74 for Awareness Raising events and 55 to 64 for 'How to' events. Figure 4 shows the number of respondents in each age group, by type of event.



**Figure 4: Number of respondents to the baseline questionnaire survey, by age group and type of event**

### Household composition

The most frequently reported household composition was living with a husband, wife or partner only (n=299, 60%). Around a quarter lived alone (116, 23%). There were also 43 (9%) respondents who lived with family members other than a partner (most frequently children, followed by parents); 19 (4%) who lived with both their spouse or partner and other family (most frequently children); 15 (3%) who lived with friends; seven (1%) who lived with their spouse or partner and other people who were not family; and five (1%) who lived only with other people who were not friends or family.

## Socio-economic roles

The most frequently reported socio-economic role was retired (233, 47%); followed by working part-time (120, 24%) and full-time (93, 19%). In addition, 24 respondents (5%) were full-time carers; 17 (3%) were full-time students; 13 (3%) were full-time home-makers; 6 (1%) were unemployed; and 5 (1%) were unable to work due to sickness or disability. Twenty-one (4%) respondents mentioned doing voluntary or church work within the free-response category of 'other'. The numbers do not add up exactly 100% because a few participants reported more than one role, most frequently combining retirement with caring, part-time work or voluntary work.

## Area of residence

Local Authority area of residence was determined using electronic linkage via National Statistics Postcode Lookup Files, and manually by name of town or village if postcode was not available. Using these methods, Local Authority area was identified for 491 (99%) respondents. The majority (91%) resided in the programme's target areas of Cheshire East (n=263, 54%) and Cheshire West and Chester (n=182, 37%). A further 9% resided in nearby Local Authority areas. This is summarized in Table 6. Due to rounding, the total percentages do not add up to exactly 100%.

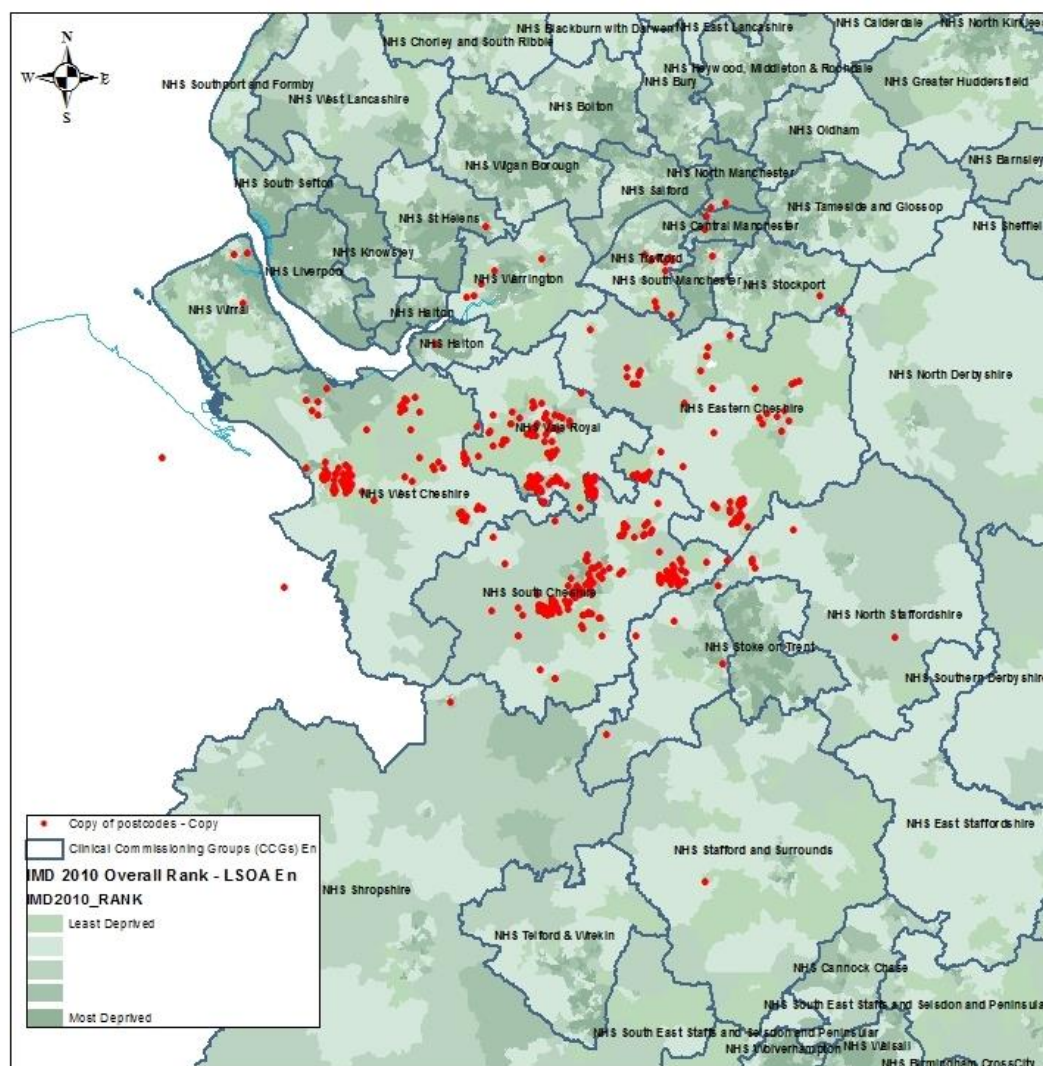
**Table 6: Number of respondents to the baseline questionnaire survey, by Local Authority of residence**

Local Authority Area	Number	Percentage
Cheshire East	263	54%
Cheshire West and Chester	182	37%
Trafford	12	2%
Manchester	6	1%
Staffordshire Moorlands	5	1%
Newcastle-under-Lyme	5	1%
Stockport	3	1%
Wirral	3	1%
*Other areas	7	1%

'Other areas' comprise one respondent each from Halton, Lancashire, Shropshire, St Helens, Stafford, Clwyd and Flintshire.



Four hundred and forty three (89%) respondents provided a valid postcode, which was mapped to a location in England (441) or Wales (2). Figure 5 shows the residential postcode location of each of these respondents as a red dot on a map. This map, provided by Public Health England, is divided by NHS Clinical Commissioning Group: NHS West Cheshire and NHS Vale Royal correspond to Cheshire West and Chester; and NHS South Cheshire and NHS East Cheshire correspond to Cheshire East. The white area of land represents North Wales.



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Dataset has no copyright message.

**Figure 5: Map of location of residence of baseline survey respondents, also showing levels of deprivation according to the English Index of Multiple Deprivation 2010**

Respondents resided throughout Cheshire, although there appeared to have been fewer than average in the NHS Eastern Cheshire area. There were clusters living in the towns and cities of Chester (n=46), Nantwich (n=36), Alsager (n=35),

Middlewich (n=34), Winsford (n=34), Crewe (n=24), Northwich (n=20), Congelton (n=19), Holmes Chapel (n=17), Sandbach (n=14), Moulton (n=11) and Macclesfield (n=10).

### **Neighbourhood deprivation**

Figure 5 illustrates levels of socio-economic deprivation by area as measured by the English Index of Multiple Deprivation, with the darkest areas showing lower level super output areas (LSOAs) within the most deprived fifth in England, and the lightest areas being within the least deprived fifth within England. It can be seen that both Cheshire East and Cheshire West and Chester have relatively low levels of deprivation as a whole, with small pockets of high deprivation. Deprived areas include much of Ellesmere Port, parts of Crewe and Chester, and small areas within Winsford, Congleton, Macclesfield and Wilmslow.

Questionnaire and national statistics data was linked to determine the level of deprivation of the respondents' locations of residence. National Statistics Postcode Lookup Files were used to link postcodes to Census 2011 lower level super output area (LSOA). LSOA was then linked to rank of English Index of Multiple Deprivation 2010 (IMD 2010) [185]. IMD 2010 ranks were divided by quintiles (fifths) within England, with one being the most deprived and five being the least deprived. There was a clear trend, with more respondents residing in the least deprived areas than the most deprived areas (13% of respondents living in the most deprived two quintiles compared with 71% living in the least deprived two quintiles). As the study area has relatively low levels of socio-economic deprivation in comparison with England as a whole, this finding is not surprising.

A similar analysis was undertaken using quintile of IMD 2010 rank within Cheshire East and Cheshire West and Chester. Four hundred and four respondents (81%) resided in Cheshire East or Cheshire West and Cheshire and could be linked by postcode to a lower level super output area. In this analysis, while respondents were more evenly distributed by level of deprivation, only 111 (27%) resided in the two most deprived fifths of LSOAs covered by the programme, compared with 206 (51%) living in the two least deprived LSOAs. This may indicate that the programme was less successful in reaching people living in deprived areas, but is not conclusive. LSOAs vary significantly in population size (nationally from 1,000 individuals to 3,000 individuals); not all individuals attending events completed a questionnaire; and not all respondents provided valid postcode data. An additional

Awareness-raising event with around 30 attendees was held in a deprived area of Chester a few days before the survey began.

Table 7 shows the number and percentage of respondents residing in LSOAs within different quintiles of IMD of England and Cheshire.

#### **6.1.4 Experience of preparing for and talking about death**

##### **6.1.4.1 Having a will**

One hundred and sixty-one respondents (33%) reported not having a will, of whom almost three-quarters (119, 74%) indicated that they were thinking of making one. Three hundred and thirty-five (68%) respondents reported having a will. A small proportion of these (43/335, 13%) indicated that they were thinking of making changes to their will.

The proportion of respondents who reported having a will varied significantly by age group, varying from 0/48 (0%) in those under the age of 35 to 72/76 (95%) in those over the age of 75 (Chi-Square test for trend  $p < 0.001$ ). A slightly higher percentage of males than females had a will (75% v 65%), but that is most likely explained by the males in the sample being, on average, older than the females.

The proportion of respondents who had a will varied by deprivation of their LSOA of residence, from 29% in the most deprived quintile to 78% in the least deprived quintile (Chi-Square test for trend  $p < 0.001$ ). The trends for both age group and neighbourhood deprivation are shown in Table 8.

**Table 8: Number and percentage of respondents to the baseline questionnaire survey who reported having a will, by age group and quintile of IMD 2010 rank within England**

Age Group		Quintile of LSOA: IMD 2010	
<b>Under 35</b>	0/48	<b>ONE</b>	4/14 (29%)
<b>35 to 44</b>	17/51 (33%)	<b>TWO</b>	21/43 (49%)
<b>45 to 54</b>	35/70 (50%)	<b>THREE</b>	45/69 (65%)
<b>55 to 64</b>	79/104 (67%)	<b>FOUR</b>	65/96 (68%)
<b>65 to 74</b>	132/147 (90%)	<b>FIVE</b>	170/218 (78%)
<b>Over 75</b>	72/76 (95%)		

**Table 7: Number and percentage of respondents to the baseline questionnaire survey residing in areas within different levels of deprivation, indicated using quintile of IMD 2010 within England and within Chester East and Cheshire West and Chester**

	England					Cheshire East and Cheshire West and Chester				
	1	2	3	4	5	1	2	3	4	5
<b>Awareness</b>	6 (2%)	28 (10%)	53 (18%)	60 (20%)	147 (50%)	18 (7%)	63 (23%)	55 (20%)	62 (23%)	74 (27%)
<b>How to</b>	8 (5%)	15 (10%)	17 (12%)	36 (24%)	71 (48%)	11 (8%)	19 (14%)	32 (24%)	40 (30%)	30 (23%)
<b>All</b>	14 (3%)	43 (10%)	70 (16%)	96 (22%)	218 (49%)	29 (7%)	82 (20%)	87 (22%)	102 (25%)	104 (26%)

Age may have been a factor in the trend by deprivation, as younger respondents tended to live in more deprived areas. However, when controlled for age group in logistic regression (combining IMD 3 and IMD 4 because the prevalence of wills was similar in each), deprivation was still a significant predictor of how likely it was that a respondent had a will. The odds ratios and P-values for each quintile compared with the least deprived quintile 5 are shown in Table 9.

**Table 8: Results of logistic regression comparing the likelihood of having a will at baseline for least deprived quintile with other quintiles of IMD, taking age group into account**

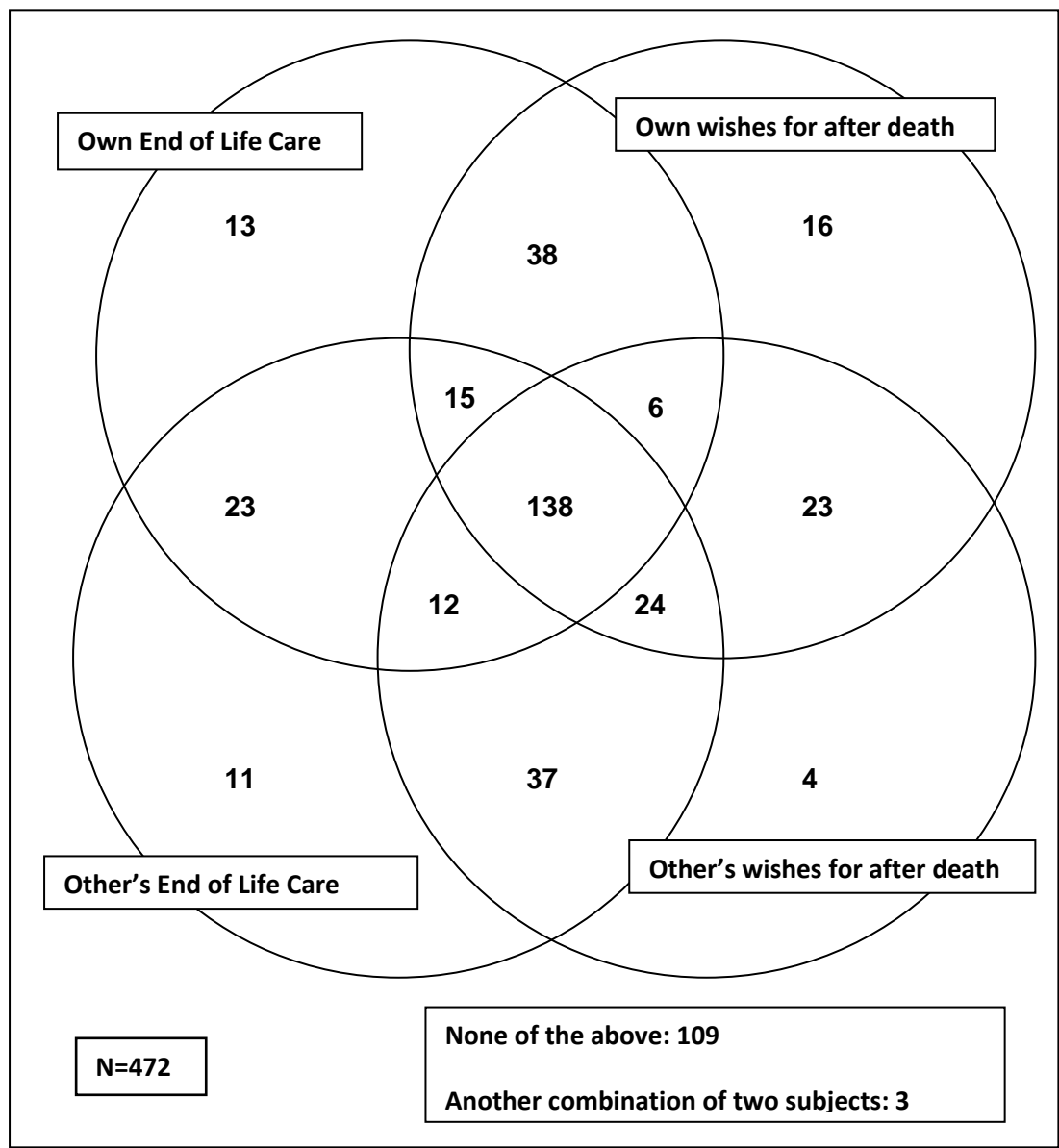
Quintile of IMD within England	Odds ratio of having a will compared with quintile 5 (95% CI)	Significance (P)
1	0.156 (0.038 to 0.633)	0.009
2	0.377 (0.156 to 0.911)	0.030
3 and 4 combined	0.538 (0.294 to 0.985)	0.044

#### **6.1.4.1 Talking about end of life preferences and bereavement**

Just over half the respondents (252, 51%) reported having discussed their own end of life care wishes with a close friend or family member; 285 (58%) had discussed what they wanted to happen after their death; and 332 (67%) reported having discussed either of these two topics. Similar proportions of respondents reported having discussed another person's end of life care wishes (263, 54%) or another person's wishes for after they have died (254, 53%), or either of these (300, 60%). Overall, 386 (78%) reported having had some discussion with friends or family about either their own or the other's wishes for end of life care and after death. A larger proportion (415, 83%) indicated that they had comforted somebody who had been bereaved. Most respondents (467, 94%) reported having either talked with friends or family about end of life wishes, or comforted somebody had been bereaved.

Respondents who reported one type of conversation about end of life wishes were more likely to report another. Of the 472 respondents who answered all four relevant questions, 138 (29%) responded 'yes' to all four, while 109 (25%) responded 'no' to all four. Only 44 (9%) responded 'yes' to only one question, while 124 (26%) responded 'yes' to two questions and 57 (12%) responded 'yes' to three questions. The most frequent combinations of two questions answered were

regarding both own end of life care and own wishes for after death (38, 8%), or both another person’s end of life care and another person’s wishes for after death (37, 8%). Figure 6 shows the different combinations of responses as a Venn diagram.



**Figure 6: Numbers of baseline survey respondents who answered ‘yes’ to whether they had talked with close friends and family on different subjects about end of life wishes**

Table 10 shows the percentage of respondents who reported having talked about both subjects, for different pairs. Of respondents who had talked about another person’s end of life care, 84% had also talked about another person’s wishes for after their death. Similarly, 76% of those who had talked about their own end of life care had also talked about their own wishes for after their death.

**Table 9: Percentage of respondents who gave the same answers to paired questions about whether they talked with close friends or family about end of life wishes**

	Own wishes for after death	Other's end of life care	Other's wishes for after death
Own end of life care	76%	73%	65%
Own wishes for after death		64%	71%
Other's end of life care			84%

**Table 10: Number and percentage of baseline survey respondents who reported having talked about different end of life wishes, by age group**

	Under 35	35 to 44	45 to 54	55 to 64	65 to 74	Over 75	Total	Chi-Squared for trend
Own wishes for end of life care	13 (27%)	20 (39%)	37 (52%)	57 (55%)	81 (55%)	44 (60%)	252/495 (51%)	<0.001
Own wishes for after death	15 (31%)	23 (45%)	46 (65%)	66 (64%)	83 (57%)	52 (74%)	285/489 (58%)	<0.001
Another's wishes for end of life care	23 (48%)	29 (57%)	43 (61%)	60 (57%)	78 (53%)	30 (42%)	263/492 (54%)	NS
Another's wishes for after death	22 (46%)	27 (54%)	48 (69%)	59 (57%)	73 (51%)	25 (36%)	254/484 (53%)	NS
Comforting somebody who has been bereaved								NS

The proportion of respondents who reported talking about their own end of life care or wishes for after their death varied by age group, with older age groups more frequently reporting these discussions (Chi-Square test for trend  $P=<0.001$ ). The trend was less clear in relation to discussing another person's wishes, with the 45 to 54 year age group reporting these discussions most often, and the over 75 reporting them least often. These patterns are shown in Table 11.

There were no differences in experience of talking about end of life wishes by sex or level of deprivation of neighbourhood of residence.

There did not appear to be any relationship between having comforted somebody who had been bereaved and age group, but this varied slightly by sex, with 86% of women and 78% of men reporting this (Pearson Chi-Square  $P= 0.029$ ).

#### 6.1.5 How comfortable talking about end of life wishes and bereavement?

Respondents were asked to rate how comfortable they felt, on a scale of 1 to 10, about talking about different end of life issues and bereavement, with 1 being completely uncomfortable and 10 being completely comfortable. This was used as an interval scale to calculate a mean score for each question. For each question, the most common rating given was 10 (completely comfortable). For each subject, the mean reported score was approximately 8. There was no significant difference in scores between the five different subjects of conversation asked about, although the mean scores were slightly lower for talking about other people's wishes than talking about own wishes. This is shown in Table 12.

**Table 11: Mean reported scores for how comfortable baseline survey respondents said they felt about talking about different end of life wishes and bereavement**

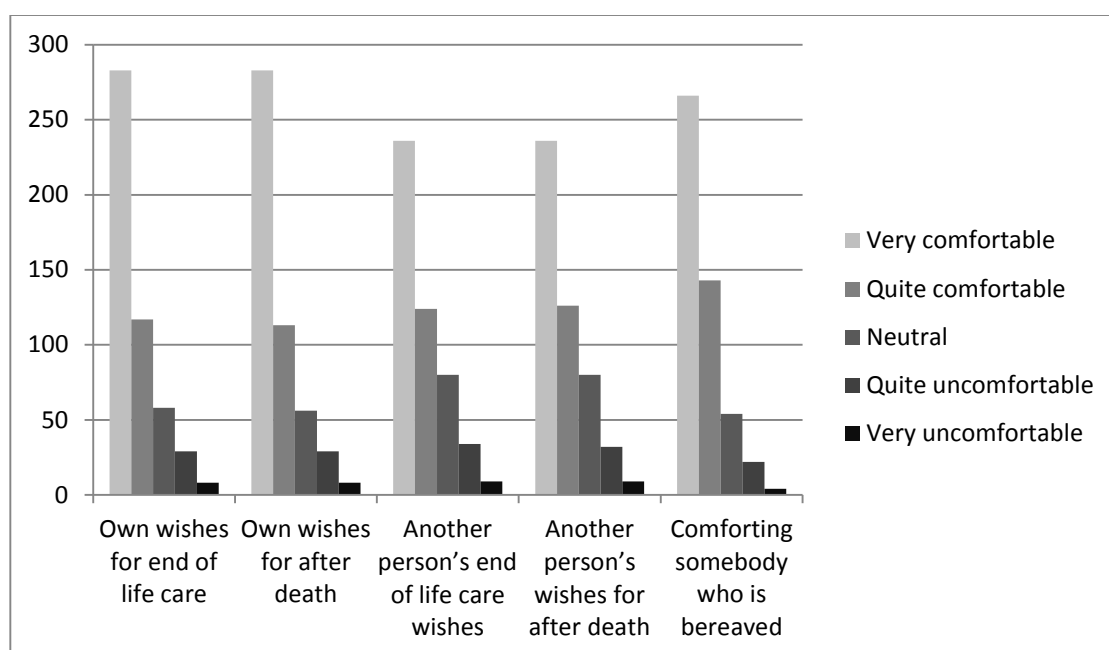
	Mean (95% CI)
Own wishes for end of life care	8.28 (8.08 to 8.48)
Own wishes for after death	8.28 (8.08 to 8.47)
Another person's wishes for end of life care	7.93 (7.73 to 8.13)
Another person's wishes for after death	7.95 (7.76 to 8.15)
Comforting somebody who has been bereaved	8.33 (8.15 to 8.51)

Scores for individuals were highly correlated between different subjects of conversation. Table 12 shows the Pearson correlation coefficients for different pairs of conversation subjects. For every pair,  $P=<0.001$ . Correlations were highest for how comfortable respondents stated they felt talking about their own end of life care



wishes and their own wishes for after their death, and for other people's end of life care wishes and wishes for after their death.

The scores were also aggregated into five categories (1-2, 3-4, 5-6, 7-8 and 9-10) to which we allocated the approximate descriptors of very uncomfortable, fairly uncomfortable, neutral, fairly comfortable and very comfortable. Figure 7 and Table 14 show the distribution of score categories for each subject of conversation.



**Figure 7: Distribution of score categories for how comfortable baseline survey respondents stated they would feel having different specific conversations relating to death and dying**

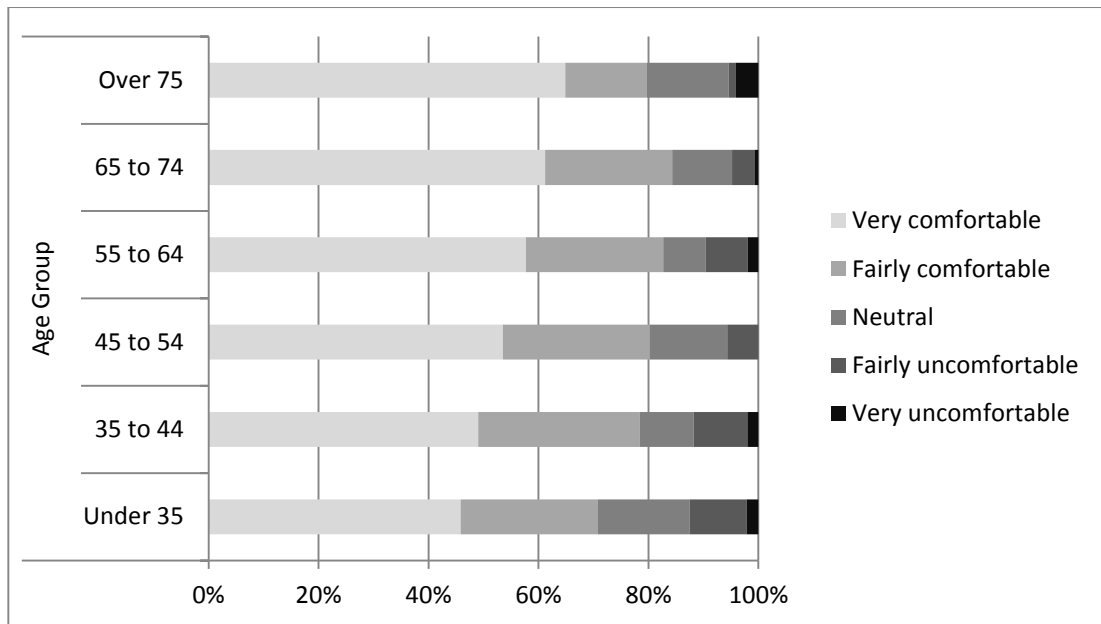
For each of the five topics of conversation, there was a clear trend, with older respondents more likely than younger respondents to say that they would be very comfortable, and less likely to say that they would feel uncomfortable. These trends are shown in Figures 8 to 12. The trend was more apparent for talking about other people's wishes than about own wishes, and was slightly different for talking about bereavement, with the youngest age group more likely to report being very comfortable than those aged 35 to 55.

**Table 12: Pearson Correlations coefficients for scores on how comfortable baseline survey respondents stated they felt talking with close friends and family about different subjects relating to end of life wishes and bereavement**

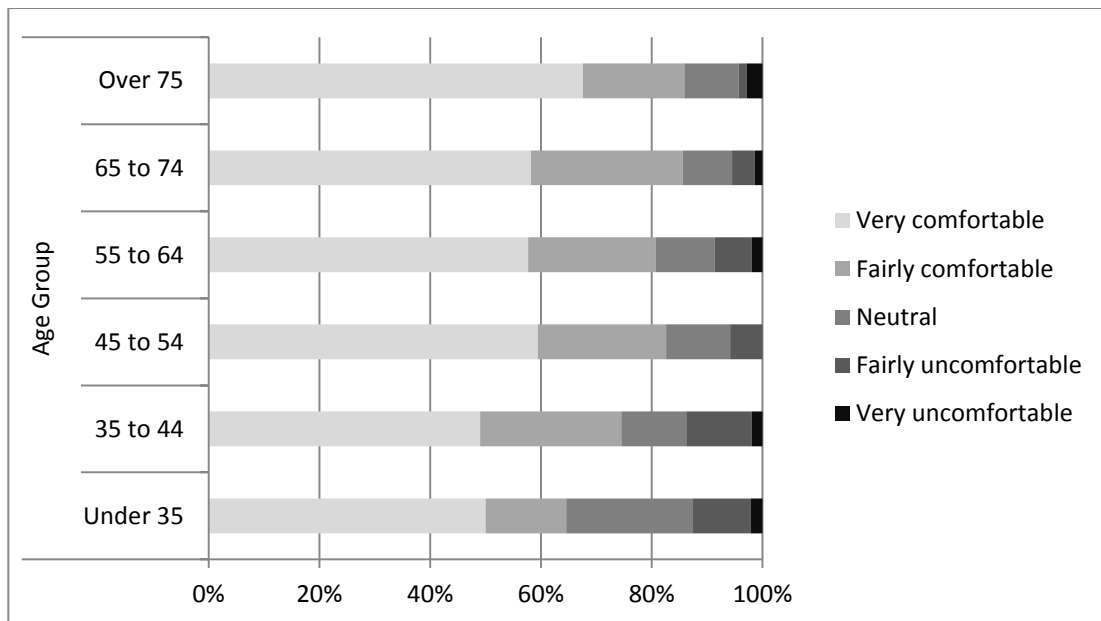
	Own wishes for after death	Another's end of life care	Other's wishes for after death	Comforting somebody who is bereaved
Own end of life care	0.865	0.657	0.664	0.508
Own wishes for after death		0.620	0.667	0.504
Another's end of life care			0.867	0.521

**Table 13: Distribution of score categories for how comfortable baseline survey respondents stated they felt talking with close friends and family about different subjects relating to end of life wishes and bereavement**

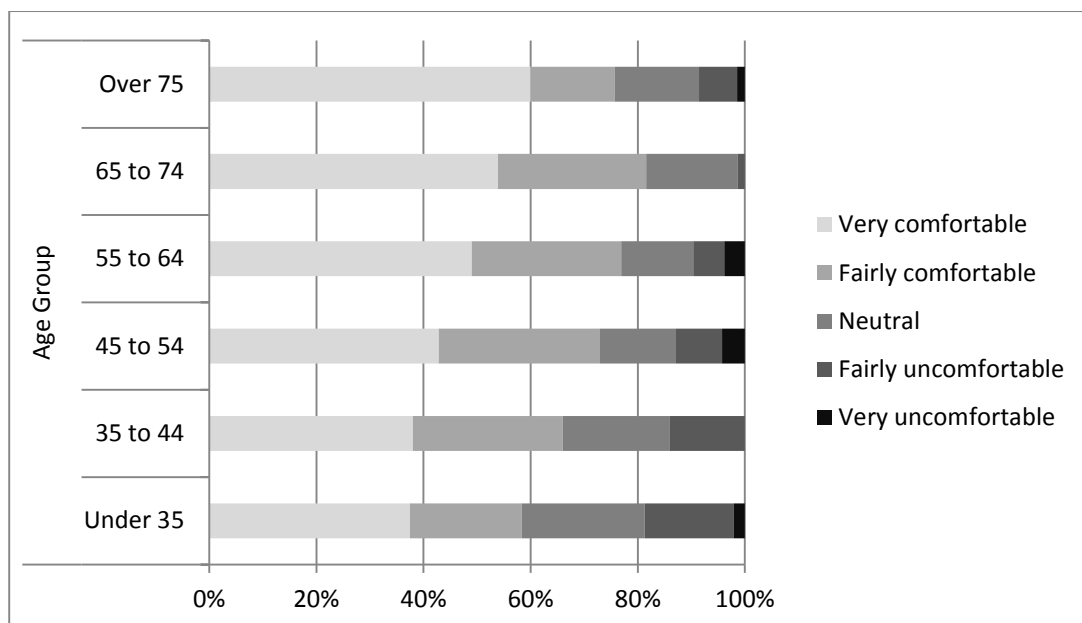
	Very uncomfortable (1 or 2)	Quite uncomfortable (3 or 4)	Neutral (5 or 6)	Quite comfortable (7 or 8)	Very comfortable (9 or 10)
Own end of life care	8 (2%)	29 (6%)	58 (12%)	117 (24%)	283 (57%)
Own wishes for after death	8 (2%)	29 (6%)	56 (12%)	113 (23%)	283 (58%)
Another's end of life care	9 (2%)	34 (7%)	80 (17%)	124 (26%)	236 (49%)
Another's wishes for after death	9 (2%)	32 (6%)	80 (17%)	126 (26%)	236 (49%)
Comforting somebody who is bereaved	4 (1%)	22 (5%)	54 (11%)	143 (29%)	266 (54%)



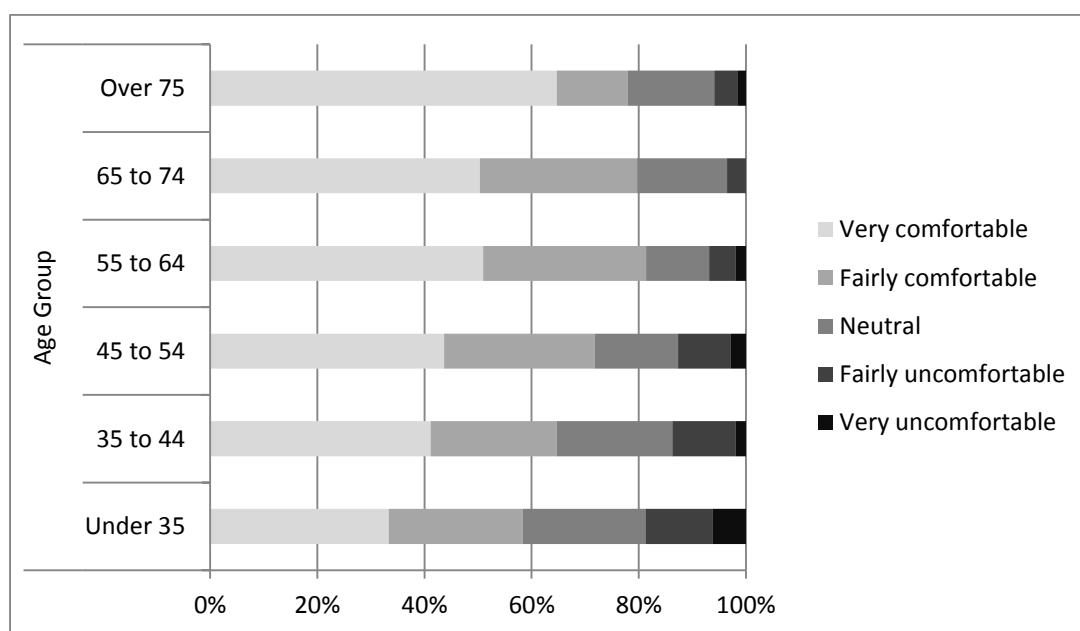
**Figure 8: Distribution of score categories by age group for how comfortable baseline survey respondents stated they would be talking about their own wishes for their end of life care**



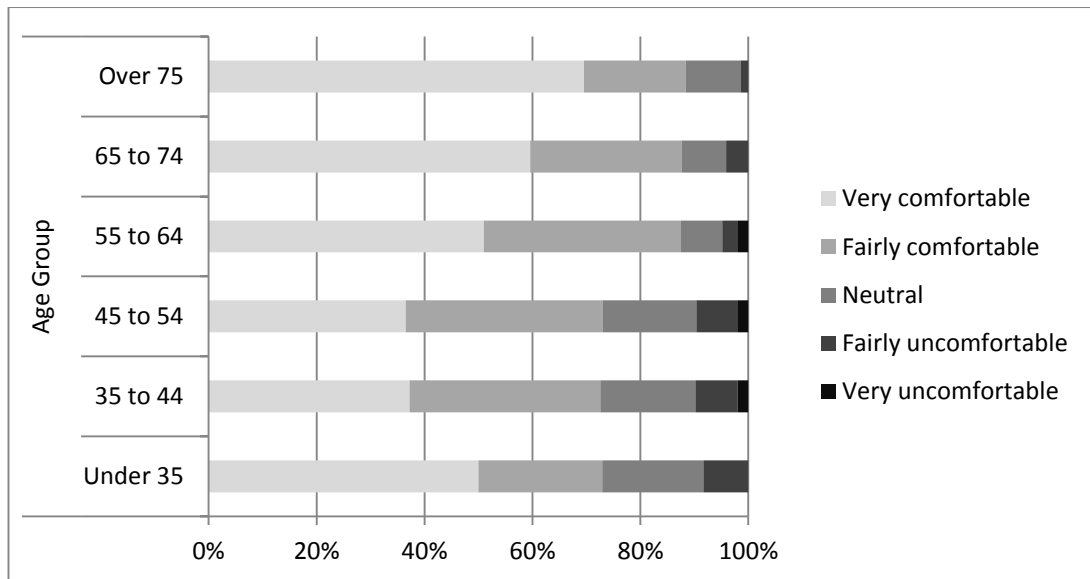
**Figure 9: Distribution of score categories by age group for how comfortable baseline survey respondents stated they would be talking about their own wishes for what happens after their death**



**Figure 10: Distribution of score categories by age group for how comfortable baseline survey respondents stated they would be talking about another person's wishes for their end of life care**



**Figure 11: Distribution of score categories by age group for how comfortable baseline survey respondents stated they would be talking about another person's wishes for what happens after their death**



**Figure 12: Distribution of score categories for how comfortable baseline survey respondents reported being about talking to comfort somebody who has been bereaved**

Table 15 shows the mean differences between reported scores for respondents under and over the age of 65, with the P-value for the differences (independent samples T-test). For each subject, respondents over the age of 65 reported feeling significantly more comfortable about talking about it than respondents under the age of 65.

**Table 14: Mean difference for how comfortable baseline survey respondents aged under and over 65 indicated that they felt about talking to close friend and family about end of life wishes or bereavement**

	Mean difference	P value
Own wishes for end of life care	0.453	0.02
Own wishes for after death	0.475	0.019
Another person's wishes for end of life care	0.724	<0.001
Another person's wishes for after death	0.657	0.001
Comforting somebody who is bereaved	0.661	<0.001

For all five topics of conversation, a slightly higher proportion of males than females reported feeling very comfortable, but the difference was not significant and could probably be explained by the males in the sample being, on average, older than the females. There was no significant difference or obvious visible trend by level of neighbourhood deprivation.

For respondents who completed at least two questions, we calculated a mean score for the different subjects, shown in Table 16. This was to allow rough comparison

with national surveys which used a single question to assess how comfortable people respondents felt talking about death (see Discussion section).

**Table 15: How comfortable baseline respondents reported being about talking to close friends and family about end of life wishes and bereavement: mean score for all five topics in the questionnaire, by age group**

	Under 35 (n=48)	35 to 44 (n=51)	45 to 54 (n=71)	55 to 64 (n=105)	65 to 74 (n=147)	Over 75 (n=75)	Total (n=497)
<b>Very uncomfortable</b>	1 (2%)	1 (2%)	0 (0%)	2 (2%)	0 (0%)	1 (1%)	5 (1%)
<b>Fairly uncomfortable</b>	2 (4%)	2 (4%)	6 (9%)	6 (6%)	5 (3%)	1(1%)	22 (4%)
<b>Neutral</b>	11 (23%)	9 (18%)	11 (16%)	8 (8%)	11 (8%)	11 (15%)	61 (12%)
<b>Fairly comfortable</b>	15 (31%)	20 (39%)	19 (29%)	38 (36%)	54 (37%)	15 (20%)	161 (32%)
<b>Very comfortable</b>	19 (40%)	19 (37%)	35 (49%)	51 (49%)	77 (52%)	47 (63%)	248 (50%)

Respondents who reported having talked about the subject in question, compared with those who had never talked about it, less often gave low scores between one and six which indicated that they were not comfortable with the subjects, and more often gave high scores of nine or ten which indicated that they were very comfortable. Having talked about a topic was therefore a significant predictor of how a comfortable a person reported being with that topic. This was highly significant for each subject, as shown in Table 17.

**Table 16: Percentage of baseline survey respondents who gave ratings of 1 to 6 ‘not comfortable’ and 9 or 10 ‘very comfortable’ talking about different topics related to end of life wishes and bereavement, by whether individuals reported having had these conversations**

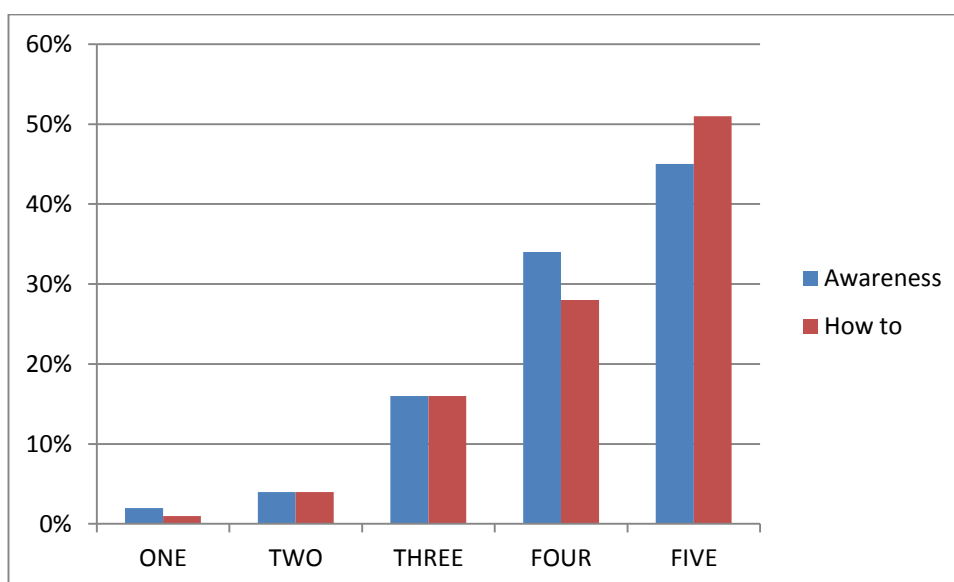
Subject talked about	Not comfortable (scores 1 to 6)		Very comfortable (scores 9 to 10)		P-value
	Yes	No	Yes	No	
Own wishes for end of life care	10%	29%	70%	44%	<0.001
Own wishes for after death	7%	36%	74%	36%	<0.001
Another person’s wishes for end of life care	15%	38%	60%	36%	<0.001
Another person’s wishes for after death	14%	37%	64%	33%	<0.001
Comforting somebody who has been bereaved	12%	41%	59%	29%	<0.001

## 6.2 'Post' Survey: Questionnaires completed immediately after CLWDW Public Health Events

### 6.2.1 Relevance of the event to the attendees

#### Ratings of relevance

Respondents were asked to rate the relevance to themselves of the event they attended, on a scale of one (completely irrelevant) to five (completely relevant). For both 'Awareness Raising' and 'How to' events, the most frequent response was five. The mean rating was 4.15 (95% CI 4.04 to 4.26) for Awareness Raising event and 4.23 (95% CI 4.08 to 4.37) for 'How to' workshops. The distributions of ratings given for each type of event are shown in Figure 13.



**Figure 13: Distribution of rating scores for relevancy of the event, for 'Awareness raising' events and 'How to' workshops**

Events attended by health and social care staff as part of their professional development were rated as more relevant than those attended by community groups (4.67, 95% CI 4.28 to 5.00 v 4.13, 95% CI 4.02 to 4.25). Awareness Raising presentations were rated as significantly more relevant by respondents aged 45 to 74 (3.41, 95% CI 3.47 to 4.16) than by those aged under 45 (3.82, 95% CI 3.47 to 4.16) or over 75 (3.79, 95% CI 3.49 to 4.10). There were no significant differences in reported relevance by sex or level of neighbourhood deprivation.

## **Most relevant themes**

Respondents were asked to indicate whether there was anything in the event that they found particularly relevant or thought-provoking, and to describe it. They interpreted the question in a variety of ways. Many did not respond, as they did not indicate that anything was particularly relevant, and some gave more than one reply. The free text responses given were analysed thematically and themes summarized numerically. Because many respondents gave very short answers, for example, 'emotional will', it was not always possible to tell exactly what they meant, so the numerical figures given are only approximate indicators.

The main themes fell into the following broad categories:

- An idea that was presented
- A specific topic of information that was presented
- Something that the event had prompted them to consider doing
- Something the event had highlighted as important in general
- Specific aspects of the event
- Positive appraisal of the event
- Criticisms of the event

The most frequently reported theme reported by respondents who attended the 'How to' workshops (31), was the ideas presented on how to have conversations about end of life wishes, reflecting the main aims of the workshops. This theme was also reported by nine respondents who had attended Awareness raising presentations.

The most frequently reported theme reported by those attending Awareness raising presentations (25) was being prompted to, or realising they needed to, talk to somebody about something, also reflecting the main aims of these events. This theme was also reported by 15 respondents who attended 'How to' workshops.

Other than ideas for conversations, ideas that were identified as particularly relevant included:

- Emotional wills (13 from Awareness raising presentations, 3 from 'How to' workshops);
- Journals or family memory books (10 from Awareness raising presentations, 3 from 'How to' workshops);



- Bucket lists (3 from Awareness raising presentations, 1 from 'How to' workshops); and
- ICE files or Life Books (2 from Awareness raising presentations, 1 from 'How to' workshops).

Topics of information that were identified as particularly relevant included:

- Wills (9 from Awareness raising presentations, 5 from How to workshops);
- Organ donation (9 from Awareness raising presentations);
- Power of attorney (3 from Awareness raising presentations, 3 from 'How to' workshops);
- End of life planning in general (4 from Awareness raising presentations); and Living wills (3 from Awareness raising presentations).

Other, minor themes, from 'How to' workshops only, were: the barriers that stop you talking (3), changing attitudes in society (2), and helping somebody with a fear of death (1).

Other than the need to talk to somebody about something, the prompts or realisations of needs most often identified as particularly relevant were:

- To review or update a will (14 from Awareness raising presentations, 1 from 'How to' workshops), or write a will (7 from Awareness raising presentations, 9 from 'How to' workshops).
- To plan a funeral or write down funeral wishes (5 from Awareness raising presentations, 1 from 'How to' workshops);
- To think about or plan for end of life generally (3 from Awareness raising presentations, 4 from 'How to' workshops);
- To write or update written instructions (3 from Awareness raising presentations, 2 from 'How to' workshops), and
- To write an emotional will (1 from Awareness raising presentations, 3 from 'How to' workshops).

Less common themes from the Awareness raising presentations included writing a journal or memory book (3); updating power of attorney (2), sending for a donor card (1), writing down bank account passwords (1), discussing guardians for children (1), and volunteering to take somebody out (1). One respondent who attended a 'How to' workshop planned to update their power of attorney.

The general realisation of the importance of different behaviours that were identified as particularly relevant included:

- Making wishes known or talking to family about wishes (7 from Awareness raising presentations, 4 from 'How to' workshops);
- Talking more about death in general (8 from Awareness raising presentations);
- Planning or organising (5 from Awareness raising presentations, 2 from 'How to' workshops);
- Making a will (4 from Awareness raising presentations, 1 from 'How to' workshops); and
- Not delaying making plans (2 from Awareness raising presentations, 2 from 'How to' workshops).

Less common themes from the Awareness-raising presentations were; seizing the day or not missing things (2); thinking about death (1); writing down wishes (1); and caring for those left behind (1).

In addition to these specific themes, 12 respondents (6 from Awareness raising presentations, 6 from 'How to' workshops) stated that the event had made them think, but did not indicate the subject of their thoughts; and eight (5 from Awareness raising presentations, 3 from 'How to' workshops) reflected on something that had happened in their past. Three respondents (1 from Awareness raising presentations, 1 from a 'How to' workshop) stated that it confirmed they already had all the necessary plans in place. Three who attended the Awareness-raising presentations said it would be useful in their professional capacity and one stated that they would be able to recommend it to other people. One respondent, who attended a 'How to' workshop stated that it had given them more confidence.

The most often appreciated components of the presentation or workshop included:

- Discussions within the group (3 from Awareness raising presentations, 9 from 'How to' workshops);
- Role plays (2 from Awareness raising presentations, 4 from 'How to' workshops); the 'Bill United' video (6 from Awareness-raising presentations); and
- Comedy clips (2 from Awareness raising presentations, 1 from a 'How to' workshop).

Twenty-seven respondents stated that they found the whole presentation relevant, useful or interesting (2 from Awareness raising presentations, 4 from 'How to' workshops); and 16 (8 from Awareness raising presentations, 8 from 'How to' workshops); made positive comments about the style of the presentation. Words used to describe the Awareness-raising presentations included, 'informative', 'light-hearted', 'warm', 'friendly', 'uplifting', 'sincere', 'sensitive', 'varied', 'challenging', 'relaxed', 'humour' and 'positive'. Words used to describe the 'How to' workshops included, 'thought-provoking', 'informative' and 'humorous'.

Three people criticised the Awareness-raising presentations, including two who stated they couldn't see it very well and one who thought it didn't have enough spiritual content. Another three criticised the 'How to' workshops, including two who mentioned that it was less relevant to young people and one who stated that it needed more structure.

### **6.2.2 Intentions to make or change a will**

Four hundred and fifty eight (92%) respondents provided data, both before and after the event, on whether they had a will, and any plans to make or change their will. Six were excluded from the analysis because their responses pre- and post-event were not compatible (i.e. suggested that they either had a will before the event and not afterwards, or vice versa). Of the 452 included in the analysis, 304 (67%) reported that they had a will and 148 (33%) reported that they did not.

Pre-event, 109 of the 148 respondents without a will (74%) indicated that they were thinking of making a will. Immediately post-event, this had increased by 24 to 133 (90%). The change comprised 26 respondents who changed from not thinking of making a will to thinking of making a will, and two respondents who changed from thinking of making a will to not thinking of making a will. The change was statistically significant (Fishers exact test  $P < 0.001$ )

Pre-event, 40 of the 304 respondents who had a will (14%) indicated that they were thinking of making changes to it. Immediately post-event, this had increased by 21 to 61 (20%). The change comprised 31 respondents who moved from not thinking of making changes to thinking of making changes, and 10 respondents who appeared to change their mind and moved from thinking of making changes to not thinking of making changes. The change was statistically significant (Liddell's exact test  $P < 0.001$ )

### 6.2.3 Intention to do something specific as a result of attending the event

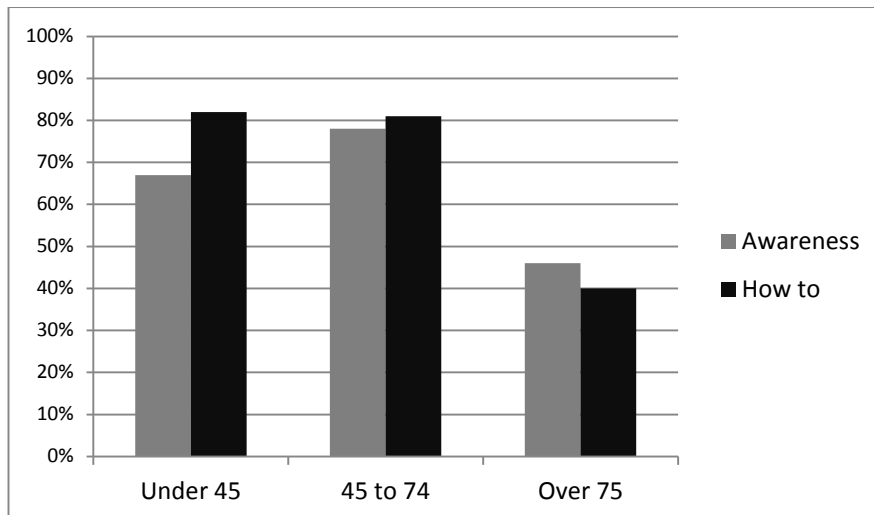
Respondents were asked both whether they had any plans to have particular conversations as a result of the event, and whether the event had inspired them to do anything else or make any other changes in their lives. They were also asked to describe any conversations and other changes that they planned. Where a respondent did not answer the question, it was assumed they were not planning any actions. Table 18 shows the percentage of respondents answering 'yes' to each question and for the two questions combined. Fifty-seven percent of respondents who attended Awareness-raising presentations and 69% of those who attended 'How to' workshops stated that they planned a specific conversation as a result. Seventy percent of respondents attending Awareness raising presentation and 79% of those attending 'How to' workshops planned either a specific conversation or another action.

**Table 17: Percentage of 'post' survey respondents who answered 'yes' to questions about whether they planned any specific conversations or other actions relating to the event they had attended**

	<b>Awareness (n=326)</b>	<b>How to (n=172)</b>
Are you planning any specific questions with family or friends because of anything you have heard today?	187 (57%)	119 (69%)
Did the presentation inspire you to do anything else or make any other changes in your life?	168 (52%)	106 (62%)
<b>Answered 'yes' to either question above</b>	<b>227 (70%)</b>	<b>136 (79%)</b>

The free text responses accompanying these questions suggested that there was some overlap between the two questions. In particular, a number of respondents described 'do anything else or make any other change' in terms of a conversation they intended to have. This suggests that most frequent immediate response to the events was to decide to have a specific conversation with somebody close.

Following the Awareness-raising event, a significantly lower proportion of respondents over the age of 75 (46%) and under the age of 45 (67%) stated that they would make changes than those or aged 45 to 74 (78%) (Chi-squared test  $P < 0.001$ ). Following the 'How to' workshops, a higher proportion of younger age groups compared (82% under 54 and 81% 45 to 74) with respondents over the age of 75 (40%) stated that they would make changes (Chi-squared test  $P = 0.007$ ). These differences are shown graphically in Figure 14.



**Figure 14: Percentage of 'post' survey respondents who answered 'yes' to questions asking if the event inspired them to have a specific conversation or make a specific change, by type of event and age group**

For the two types of event combined, respondents who had not previously discussed their own wishes for end of life care or wishes for after their death were more likely to report planning to do something as a result of attending the event than those who reported having had these conversations (67% v 79%,  $P=0.001$ ; and 69% v 79%,  $P=0.011$ ).

For each type of event and for both types combined, there was no significant variation in reported intentions to take some action by sex, rank of LSOA deprivation, or whether a respondent reported talking about another person's end of life care or wishes for after their death.

#### **6.2.4 Intended actions as a result of attending events**

Respondents who indicated on the questionnaire that they planned to have a specific conversation or take another action were also asked to briefly describe the conversation or action planned. This data was summarized thematically. In cases where respondents described two different conversations or actions, both were included. Where respondents described a conversation in answer to the question about other actions, or vice versa, the answer was included in the analysis according to its actual theme. As the answers given were generally very brief, the data is incomplete and in some cases was difficult to interpret. Therefore the numbers presented are intended as a guide only, reflected in the pragmatic stance of this research.

#### **6.2.4.1 Conversations**

Of the 187 respondents who attended Awareness Raising events and indicated that they planned a specific conversation as a result, 152 also briefly described that conversation. The majority planned conversations with a spouse, parent(s) or child. Others planned conversations with siblings, grandparents, aunts, uncles, or friends.

Of the 119 who attended 'How to' workshops and indicated that they planned a specific conversation as a result, 82 also briefly described that conversation. The majority planned to talk to spouses, partners, family members and friends. One respondent planned conversations with the palliative care patients she worked with, and one planned conversations with colleagues.

The contents of the planned conversations were categorized into the following themes:

- End of life wishes
- Financial and practical arrangements
- General discussion
- Passing the message on to other people
- Other

Most frequently, respondents stated that they planned to talk about their own end of life or funeral wishes (59 from Awareness raising presentations, 16 from 'How to' workshops), or have a mutual conversation with another person about both their wishes (56 from Awareness raising presentations, 19 from 'How to' workshops). The next most frequent type of conversation described were about another person's end of life or funeral wishes (27 from Awareness-raising presentations, 19 from 'How to' workshops). As might be expected, conversations about own wishes were planned most often with children, mutual conversations about both people's wishes were planned most often with spouses, and conversations about another person's wishes were planned most often with a parent or other older relative.

Another relatively frequently planned conversation subject was organising the practicalities of financial arrangements for after death, most often with a spouse (14 from Awareness-raising presentations, 13 from 'How to' workshops); while seven respondents (6 from Awareness-raising presentations, 1 from a 'How to' workshop) planned to give practical information to their children about where wills and other

important documents were kept, and six planned another type of discussion about wills (4 from Awareness-raising presentations, 2 from 'How to' workshops).

Twenty-eight respondents (23 from Awareness-raising presentations, 5 from 'How to' workshops) stated that they planned to have a general discussion, with no specific subject in mind.

Some respondents planned to take the messages of the presentation further, with 14 (9 from Awareness-raising presentations, 5 from 'How to' workshops) planning to persuade a family member or friend to talk about their wishes, prepare for the end of their life or make a will, and six, all of whom attended 'How to' workshops, planning to tell a friend or colleague about the workshop or its contents.

A few respondents planned conversations that were not directly related to planning for end of life or discussing end of life wishes. Four (2 from Awareness-raising presentations, 2 from 'How to' workshops) planned to talk with family about recent family bereavements, while one respondent who attended a 'How to' workshop specifically wanted to discuss plans for a family member's ashes. Another four (2 from Awareness-raising presentations, 2 from 'How to' workshops) planned to talk about their own or family history; three, all from 'How to' workshops planned to talk about the future generally, and one, also from a 'How to' workshop planned to resolve old family arguments and misunderstandings.

In addition, three respondents, one who attended an Awareness Raising presentation and one who attended a 'How to' workshop, stated that they would listen to family members who wanted to talk about their wishes.

Table 19 lists the specific topics of conversation planned by respondents who described plans to talk about their own wishes, mutual wishes or another person's wishes. The majority either did not specify the exact subject or said 'all subjects'. The most commonly described specific subjects were funeral wishes or arrangements, followed by end of life care and organ donation. Because the answers given were short and sometimes unclear, it was not always possible to be sure that we had understood the respondents meaning exactly, in which case a 'best guess' was used. Some respondents described both a general conversation and another specific conversation.

**Table 18: Intended end of life topics of conversation resulting from attending the events, as indicated by 'Post' survey respondents**

Topic of Conversation	Awareness	How to
'Wishes', 'end of life wishes' or a 'all subjects'	63	39
Funeral arrangements/ wishes	37	11
End of life care or issues such as resuscitation	17	5
Organ donation	11	0
Plans for old age or the future in general	2	2

#### **6.2.4.2 Other actions**

Of the 168 respondents who attended Awareness Raising presentations and indicated that they planned to take a relevant action other than a specific conversation, 118 briefly described what that action was. Of the 106 respondents who attended Awareness Raising presentations and indicated that they planned to take some action other than a specific conversation, 81 briefly described what that action was.

The main themes identified were:

- Practical preparations for end of life and death
- Emotional preparations for end of life and death
- Living life differently
- Communicating differently
- Having a different attitude to death
- Passing on the messages of the event

The most frequently described intentions were related to wills. Twenty four respondents (14 from Awareness-raising presentations, 10 from 'How to' workshops) indicated that they planned to make a will, while 23 (20 from Awareness-raising presentations, 10 from 'How to' workshops) indicated that they planned to change or review their existing will. A further seven (one from an Awareness raising presentation, 6 from 'How to' workshops) indicated that they would think about making a will. The difference between the two types of event might relate to the fact that respondents attending the 'How to' workshops tended to be younger than those attending Awareness-raising presentations.

The second most frequent sub-theme relating to practical preparations for end of life and death related to funeral preparations, with 12 respondents (7 from Awareness-raising presentations, 5 from 'How to' workshops) intending to plan a funeral; six



intending to write down their funeral wishes (4 from Awareness-raising presentations, 2 from 'How to' workshops); and six (2 from Awareness-raising presentations, 4 from 'How to' workshops); intending to think about their funeral wishes.

Six respondents planned to do something relating to organ donation, including 3 who intended to obtain a donor card; one who intended to check a donor card; and two who planned to look into organ donation or leaving their body to medical science.

Five respondents planned to do something relating to power of attorney, including two who planned to arrange power of attorney (1 from an Awareness-raising presentation, 1 from a 'How to' workshop), and, from the Awareness-raising presentations, one who planned to arrange power of attorney and three who said they would think about power of attorney.

Other practical preparations mentioned included making a living will (2 from Awareness-raising presentations) and thinking about guardians for children (2 from Awareness-raising presentations).

Several respondents mentioned general preparations which seemed to be of a practical nature, but were described in vague terms. These included writing their wishes down, or updating written wishes (13 from Awareness-raising presentations, 5 from 'How to' workshops); making or updating plans (5 from Awareness-raising presentations, 7 from 'How to' workshops); and thinking about making plans or preparations (1 from Awareness-raising presentations, 2 from 'How to' workshops);

Less formal practical preparations included tidying, de-cluttering or organising things (5 from Awareness-raising presentations, 2 from 'How to' workshops) and starting a Life Book or ICE file (1 from an Awareness-raising presentation, 4 from 'How to' workshops).

Emotional preparations for end of life were planned by a number of respondents. The most frequent type was planning an emotional will or a letter for relatives to open after their death (17 respondents, 11 from Awareness-raising presentations, 6 from 'How to' workshops). A further three (12 from Awareness-raising presentations, 1 from a 'How to' workshop) were considering an emotional will. Starting a journal or recording personal or family history was another frequent response (14 respondents, 6 from Awareness-raising presentations, 8 from 'How to' workshops).

One respondent from an Awareness-raising event stated that they planned to find out about their dad's life, and another wrote that they would think about their own mortality.

Only three respondents mentioned making preparations relating to end of life care; these included one respondent from a 'How to' workshop who stated that they were going to make plans for the event of sickness, and another two who planned to think about end of life care wishes.

Another frequent theme was planning to live differently. Twenty four respondents (16 from Awareness-raising presentations, 8 from 'How to' workshops) wrote that they would live well, live life or the full, or other similar sentiment; 20 (13 from Awareness-raising presentations, 7 from 'How to' workshops) stated they would make a bucket list; and five (3 from Awareness-raising presentations, 2 from 'How to' workshops) said they would appreciate other people more. One person wrote that they would try harder to lose weight and exercise and one that they would have a greater sense of urgency.

On the theme of supporting other people more, seven respondents stated they would support other people more if they were ill or bereaved (3 from Awareness-raising presentations, 2 from 'How to' workshops); two (both from Awareness-raising presentations) that they would do voluntary work; one would allow more time for their team; and one wrote that they would forgive themselves.

A number of respondents stated that they would communicate differently about death, including 15 (7 from Awareness-raising presentations, 8 from 'How to' workshops) who wrote that they would be more open, upfront or have more conversations; 10 (6 from Awareness-raising presentations, 4 from 'How to' workshops) who stated they would be more confident about talking about death; and nine (4 from Awareness-raising presentations, 5 from 'How to' workshops) who stated they would listen better or be more receptive to others. Two respondents (1 from an Awareness-raising presentation, 1 from a 'How to' workshop) said they would use humour more and two (1 from an Awareness-raising presentation, 1 from a 'How to' workshops) said they would talk more positively about death. One participant from a 'How to' workshop wrote, "The way we approach the 'D' word" and one from an Awareness-raising presentation stated that they would ensure people listened to them.

One person each stated that they would open up other difficult conversations and be more open about 'taboo' subjects.

Seven respondents stated that they would have a different attitude to death including three (1 from an Awareness-raising presentation, 2 from 'How to' workshop) who stated that they would be more aware of the issues; two (both from 'How to' workshops) who said they would come to terms with death or deal with it better; and two (1 from an Awareness-raising presentation, 1 from a 'How to' workshop) who said they would think more positively or openly about death.

Four respondents from Awareness-raising presentations mentioned passing the messages of the presentation on to other people; including two who reported their intention to arrange a similar event, one who intended to discuss the issues at a church pastoral committee; one who intended to encourage a network support group; and one who stated that they would involve family and community. One respondent who attended a 'How to' workshop stated that he would continue to write about the subject.

## **6.3 Follow up Survey: three months after events**

### **6.3.1 Response rate**

Of the 214 people who gave their permission to be contacted, 200 gave a valid postal address, and one person provided their postal address after being contacted by email. Of the 201 people who were sent follow-up questionnaires, 141 (70%) returned a completed questionnaire. This represented a total follow up rate of 141/498 (28%). Of these, 100 completed a baseline questionnaire at an awareness event and 41 completed a baseline questionnaire at a 'How to' workshop. Fifteen respondents indicated on the follow-up questionnaire that they had attended both an awareness-raising event and a 'How to' workshop.

### **6.3.2 Follow-up period**

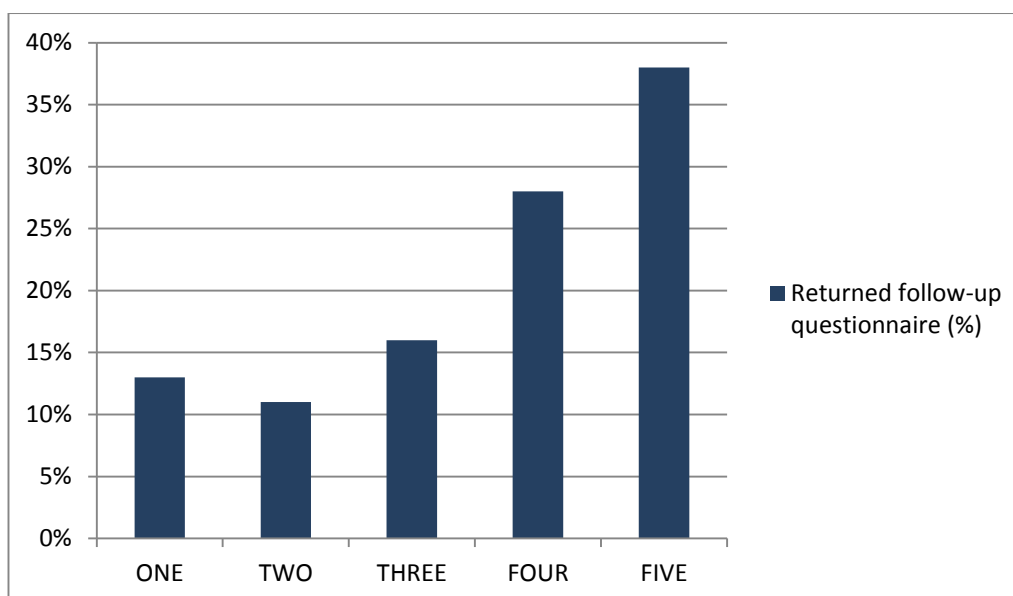
The median time between completion of baseline and follow-up questionnaires was 13 weeks six days, with a range between 11 weeks three days to 30 weeks two days.

### **6.3.3 Characteristics of responders and non-responders**

The group of respondents who returned follow-up questionnaires (responders) differed significantly from the non-responders who either did not give permission for follow-up or did not return a questionnaire.

A larger proportion of responders were aged between 45 and 74 (110/141 (78%) v 213/357 (60%)) and a lower proportion were aged under 45 (18/141 (13%) v 81/357 (23%)) or over 74 (13/141 (9%) v 63/357 (18%)) (Chi-squared test  $p=0.001$ ). The response rate for respondents aged 45 to 74 was 34% compared with 18% for those under the age of 45 and 17% for those over the age of 75.

Respondents who rated the events as more relevant to them were more likely to return follow-up, and this was a significant trend (chi-squared test for trend  $p<0.001$ ). The trend is shown in Figure 15:



**Figure 15: Follow-up rate for respondents by their rating of the relevance of the event they attended**

A significantly higher proportion of follow-up responders than non-responders had indicated pre-event that they had talked to somebody close to them about their own or the other person's end of life and final wishes. This is shown in Table 20.

**Table 19: Percentage of baseline survey respondents who reported having conversations with close friends and family about end of life wishes, by whether they responded to follow-up**

Topic of Conversation	Responder	Non-responder	P-value
Own end of life care	85/140 (61%)	167/355 (47%)	0.006
Own wishes for after your death	96/140 (69%)	189/349 (54%)	0.003
Another person's end of life care	97/141 (69%)	166/351 (47%)	<0.001
Another person's wishes for after their death	94/140 (67%)	160/344 (47%)	<0.001

A higher proportion of responders had stated in the 'Post' survey that they planned to take some action or make some change as a result of their attending the event (118/141 (84%) v 245/357 (69%), chi-squared test  $P=0.001$ ).

Responders also reported significantly higher scores pre-event for how comfortable they were about having conversations about their own and other people's end of life and final wishes. This is shown in Table 21.

**Table 20: Mean difference for how comfortable baseline survey respondents indicated they felt about talking about end of life wishes and bereavement, for responders and non-responders to the follow-up survey**

Topic of Conversation	Mean difference	P-value
Own end of life care	0.642	0.001
Own wishes for after own death	0.613	0.001
Another person's end of life care	0.737	<0.001
Another person's wishes for after their death	0.648	0.002
Comforting somebody who is bereaved	0.327	0.087 NS

There were no significant differences between responders and non-responders in sex, level of deprivation of area of residence, whether they attended an Awareness-raising presentation or 'How to' workshop, or whether the event they attended was intended for health and social care professionals in particular or for any member of the public.

#### **6.3.4 Wills**

Data on wills and intentions regarding wills was available before, post, and at follow-up for 133 respondents (95% of follow-up, 27% of total). One respondent appeared to have a will pre-event but no will at follow-up; this was assumed to be a mistake and data for this individual was excluded from the analysis. Of the remaining 132 (94 from Awareness raising presentations, 37 from 'How to' workshops), 98 (74%; 77 (82%) from Awareness-raising presentations, 20 (54%) from 'How to' workshops) reported having a will pre-event and 34 (26%; 17 (18%) from Awareness-raising presentations, 17 (46%) from 'How to' workshops) did not have a will.

##### **6.3.4.1 Respondents who did not have a will at baseline**

The majority (29/34, 85%) of the respondents who did not have a will at baseline indicated at that point that they were thinking of writing one, and all 34 stated at some point in the survey that they were considering making a will. Between pre-event and follow-up, two respondents changed from thinking about making a will to making a will, four changed from not thinking of making a will to thinking of making a will, and one changed from thinking of making a will to not thinking of making a will. Another respondent changed from not thinking of making a will pre-event, to thinking of making a will immediately post-event, to appearing to change their mind

and not planning to make a will again at follow-up. These patterns are shown in Table 22. Due to the small numbers involved, no statistical tests were undertaken.

The results appeared similar for Awareness-raising presentations and 'How to' workshops, although the numbers were very small. One respondent from each event type indicated that they had a will at follow-up, and two respondents from each event type indicated that they were not thinking of making a will before the event, but by follow-up indicated that they were thinking of making a will.

To determine whether any of these changes were associated with the events that respondents attended, responses to these fixed-choice questions about wills were cross-referenced with participant's free text responses to other questions.

Of the two respondents who reported making a will between baseline and follow-up, one reported that they had made a will because of the event (quote: 'Have made a will after discussing with my wife following the workshop. We were able to use information from the workshop to help us to go about making the will'), while one did not mention their will elsewhere in the questionnaire.

Of the four respondents who changed from not thinking of making a will to thinking of making a will, one reported in free text responses immediately post-event that they realised it was selfish of them not have to have will, and that they planned to make a will. At follow-up the same person stated that they were going to see a will advisor. Another mentioned they were still thinking about it. The remaining two did not mention their will elsewhere in the questionnaire.

Of the 26 respondents who indicated that they were considering making a will at all three time-points, two mentioned that they had made definite plans to make or formalise a will as a result of attending the event, and another two stated that they planned to organise it soon. One reported definite plans to write a will pre-event and was discussing this with friends both before and during the follow-up period. Two did not mention any specific plans, but stated that the information on wills was particularly relevant to them. Nine mentioned after the event that it had led them to plan to make, or discuss making, a will, but did not provide any information at follow-up about whether they had made any progress towards that. Another nine made no reference to their own will elsewhere in the questionnaire.

**Table 21: Number and percentage of follow-up survey respondents who did not have a will at baseline who answered ‘yes’ to whether they were thinking of making a will and whether they had a will at different time points in the survey**

Combination			Number (%)			No. thinking of making a will			No. with a will
Before	After	Follow-up	Awareness	How to	Total	Before	After	Follow-up	Follow-up
Yes	Yes	Yes	12 (71%)	13 (76%)	25 (74%)	25	25	25	0
Yes	Yes	No	1 (6%)	0	1 (3%)	1	1	0	0
Yes	No	No	0	1 (6%)	1 (3%)	1	0	0	0
No	No	Yes	1 (6%)	0	1 (3%)	0	0	1	0
No	Yes	Yes	1 (6%)	2 (12%)	3 (9%)	0	3	3	0
No	Yes	No	1 (6%)	0	1 (3%)	0	1	0	0
Yes	Yes	Have a will	1 (6%)	1 (6%)	2 (6%)	2	2	0	2
<b>Totals</b>			<b>17</b>	<b>17</b>	<b>34</b>	<b>29</b>	<b>32</b>	<b>29</b>	<b>2</b>

**Table 22: Number and percentage of follow-up survey respondents who had a will at baseline who indicated that they were thinking of making changes to their will at different time-points in the survey**

Combination						Total ‘Yes’		
Before	After	Follow-up	Awareness	How to	Total	Before	After	Follow-up
Yes	Yes	Yes	5 (14%)	2 (10%)	7 (7%)	7	7	7
Yes	Yes	No	2 (3%)	0	2 (2%)	2	2	0
Yes	No	Yes	2 (3%)	2 (10%)	4 (4%)	4	0	4
No	No	No	58 (75%)	12 (57%)	70 (71%)	0	0	0
No	No	Yes	4 (5%)	3 (14%)	7 (7%)	0	0	7
No	Yes	Yes	1 (1%)	1 (5%)	2 (2%)	0	2	2
No	Yes	No	5 (6%)	1 (5%)	6 (6%)	0	6	0
<b>Totals</b>			<b>77</b>	<b>21</b>	<b>98</b>	<b>13 (13%)</b>	<b>17 (17%)</b>	<b>20 (20%)</b>



In summary, there is evidence at follow-up that as a result of the events:

- One respondent had made a will
- Three respondents were in the process of organising or formalising a will
- Two respondents had made a definite decision to make a will

A further 11 people appeared to have thought further about making a will, but may not have done anything about it.

#### ***6.3.4.2 Respondents who had a will at baseline***

The analysis for respondents who already had a will at baseline was complicated by the fact that a change from 'thinking of making changes' to 'not thinking of making changes' could indicate that changes have already been made, that the will has been reviewed and changes found unnecessary, or that no action has been taken.

Of the 98 respondents who had a will at baseline, 13 (13%) indicated they were thinking of making changes. This increased to 17 (17%) immediately after events and 20 (20%) at follow-up. The majority of respondents (77, 78%) did not change their responses over the three time points, including 70 (71%) who indicated they were not thinking of making changes and 7 (7%) who indicated that they were thinking of making changes.

Of those who changed their response between different time-points on the survey:

- Seven (7%) stated they were not thinking of making changes to their will either pre- or post-event, but then were considering making changes at follow-up.
- Six (6%) changed from not considering changes pre-event to considering changes immediately post-event to not considering changes again at follow-up.
- Two (2%) changed from not thinking about making changes pre-event to thinking of making changes at both post-event and follow-up, and
- Two (2%) changed from thinking about making changes pre- and post-event, to not thinking of making changes at follow-up.

There did not appear to be any significant differences between the two types of event, although, due to the small numbers involved, this was not tested statistically.

Table 23 shows all the sequence combinations in the survey for whether the respondents reported thinking of making changes to their will at the three time points where it was asked; immediately pre-event, immediately post-event and at follow-up, by type of event.

To determine whether any of these changes were associated with attending the events, for respondents who indicated at any point in the survey that they were thinking of making changes to their will, their sequences of responses was cross-referenced with the free-text responses they gave to other questions.

Of the eight respondents who changed from not thinking of making changes to thinking of making changes between pre-event and immediately post-event, five reported that the event was a prompt for them to review their will, of which one reported at follow-up that they had updated their will because of the event, and one reported that they were in the process of updating their will because of the event. The remaining three respondents made no mention of wills in elsewhere in the questionnaire

Of the seven respondents who changed from not thinking of making any changes pre- and post-event to thinking of making changes at follow-up, one stated that the event had prompted them to check their arrangements, three mentioned wills as aspect of the event that was of particular relevance to them, and one mentioned planning to talk to their children about the will. The remaining two made no mention of a will elsewhere in the questionnaire.

Of the seven respondents who were thinking of making changes to their will at all three time points, one stated that they were making steps to change their will because of the event, rather than just talk about it. The remaining six made no mention of wills in their free text responses.

In summary there is evidence at follow-up that because of the events, one respondent had changed their will and will were in the process of changing their will.

A further four mentioned that they were prompted to think of reviewing their will, but there is no follow-up data available to check whether they did this or not, and four started thinking about making changes and gave some indications that they event may have encouraged them in some way.

### **6.3.5 Experience of talking about subjects relating to end of life wishes or bereavement**

Identical questions were asked at baseline and at follow-up regarding whether respondents had talked with close friends and family about different end of life wishes or comforted somebody who had been bereaved. For each subject, a number of respondents reported changing from having never had the conversation to having had the conversation. A smaller number also apparently changed from having had the conversation to having never had the conversation, which is obviously impossible. Therefore, in order not to exaggerate any apparent effects, the data is presented as total numbers and percentages before and after. A one-sided statistical test, Liddell's exact test, was conducted to compare proportions before and after. The results are summarised in Table 24.

There was no significant difference between pre-event and follow-up in the number of respondents who reported having had a conversation about another person's wishes for their end of life care or what they wanted after their death, or in the number who had talked to comfort somebody who had been recently bereaved. However, there was a significant increase (9% of the total sample) in the number of people reporting having had a conversation about their own wishes for their end of life care or what they would wish to happen after their death.

To triangulate these findings as a method for estimating the number of people who had had these conversations for the first time sometime between the baseline survey and follow-up, cross checks were made with responses other questions within the questionnaire.

Eighteen respondents reported having talked about either their own end of life care or own wishes for what they would want to happen after their death at follow-up but not pre-event. Of these, 13 indicated that they had talked about their own end of life wishes since the event; 12 (67%, 95% CI 44% to 84%) indicated that it was because of the event. This also gives an estimate of nine percent of the sample who had a conversation about their own end of life wishes for the first time as a result of attending the event.

**Table 23: Number and percentage of follow-up survey respondents who indicated that they had talked to close friends and family about end of life wishes, or comforted somebody who had been bereaved, at baseline and follow-up, and change between the two time points**

	Before			Follow-up			Difference			P value
	Aware ness	How to	Total	Aware ness	How to	Total	Aware ness	How to	Total	Total
<b>Own end of life care</b>	59/99 (60%)	26/40 (65%)	85 (61%)	70/99 (71%)	27/40 (68%)	97 (70%)	11%	3%	9%	0.033
<b>Own wishes for after your death</b>	70/99 (71%)	26/40 (64%)	96 (69%)	79/99 (80%)	29/40 (73%)	108 (78%)	9%	9%	9%	0.033
<b>Other's wishes for end of life care</b>	66/100 (66%)	29/39 (74%)	95 (68%)	68/100 (68%)	27/39 (69%)	95 (68%)	2%	-5%	0%	N/A
<b>Other's wishes for after their death</b>	67/98 (68%)	24/39 (85%)	91 (66%)	67/98 (68%)	26/39 (74%)	93 (68%)	0%	2%	2%	0.44 (NS)
<b>To comfort somebody who is bereaved</b>	86/100 (86%)	36/39 (92%)	122 (88%)	83/100 (83%)	34/39 (87%)	118 (85%)	-3%	-5%	-3%	N/A

A further check was made to assess the internal consistency of these questions in the questionnaire. Ten respondents reported never talking about their own wishes for either end of life care or what they would want to happen after their death at follow-up, yet reported pre-event that they had had at least one of these conversations (an impossible combination). In answer to a different question, five of these reported that they had talked about their own end of life wishes since the event, with all five of them saying that it was because of the event. Therefore it appears that in at least half of the cases where respondents appeared to change having had a conversation to having never had that same conversation, it was the later response which was inaccurate.

### 6.3.6 How comfortable talking about end of life wishes and bereavement

There were no significant differences in mean reported scores for how comfortable respondents indicated they felt about talking to close friends and family about different end of life wishes, or comforting somebody who had been bereaved, pre-event and at follow-up. The means scores and 95% confidence intervals at both time periods are shown in Table 25.

**Table 24: Mean baseline and follow-up rating scores for how comfortable follow-up survey respondents felt talking about different end of life wishes and comforting somebody who had been bereaved**

	<b>Baseline (95% CI)</b>	<b>Follow-up (95% CI)</b>
Own end of life care	8.73 (8.45 to 9.01)	8.73 (8.47 to 8.99)
Own wishes for after your death	8.71 (8.42 to 8.99)	8.75 (8.48 to 9.03)
Other's wishes for end of life care	8.46 (8.15 to 8.76)	8.20 (7.87 to 8.53)
Other's wishes for after their death	8.40 (8.08 to 8.72)	8.29 (7.95 to 8.62)
To comfort somebody who is bereaved	8.55 (8.28 to 8.82)	8.46 (8.16 to 8.76)
<b>Mean score</b>	<b>8.58 (8.34 to 8.82)</b>	<b>8.48 (8.23 to 8.74)</b>

The majority of respondents gave similar responses at baseline and follow-up. When describing how comfortable they felt talking about their own wishes for end of life care, 78 of 140 (56%) gave the same score at baseline and follow-up, 108 (77%) were within one point of baseline and 123 (88%) were within two points. There was no significant difference by type of event.

For every topic of conversation, the mean change in score varied according to baseline score. Lower baseline scores were associated with higher positive

changes. A baseline score of ten was associated with a negative change; this was the only possible direction of movement, as ten was the maximum score.

Baseline scores of six or under were associated with a positive change, baseline scores of 7 to 9 were associated with very small positive or negative changes, and a score of ten was associated with a significant negative change. Table 26 shows this pattern for each question.

**Table 25: Mean change in scores between baseline and follow-up for how comfortable respondents indicated that they felt about talking about different end of life wishes and bereavement, by baseline score**

Topic of conversation	Baseline score		
	1 to 6 (95% CI)	7 to 8 (95% CI)	10 (95% CI)
Own end of life care	2.00 (0.99 to 3.01)	0.16 (-0.19 to +0.5)	-0.71 (-1.02 to -0.40)
Own wishes for after your death	2.29 (0.83 to 3.74)	0.07 (-0.33 to +0.47)	-0.47 (-0.74 to -0.21)
Other's wishes for end of life care	1.09 (-0.5 to +2.18)	-0.18 (-0.71 to +0.32)	-0.98 (-1.40 to -0.61)
Other's wishes for after their death	1.70 (0.63 to 2.77)	0.41 (-0.95 to +0.12)	-0.60 (-0.93 to -0.27)
To comfort somebody who is bereaved	0.62 (-0.77 to +2.10)	-0.03 (-0.39 to +0.35)	-0.05 (-0.76 to -0.26)

Because the majority of negative change in the sample was associated with a decrease in score from 10 to 9, and there were a large number of individuals gave a rating score of ten before the event, this ceiling effect could disproportionately affect the overall change in mean score.

To control for ceiling and floor effects, a further comparison of baseline and follow-up scores was undertaken, excluding individuals with the highest and lowest scores (1 and 10) at baseline. In this analysis, for both types of event combined, the mean change in score from baseline to follow-up was positive for every subject. This reached statistical significance for how comfortable respondents were in talking about their own wishes for end of life care, but the differences appeared to be relatively small. There were no significant differences between Awareness-raising presentations and 'How to' workshops. Table 27 shows these findings for both types of event combined.

There were no significant differences between change in how comfortable respondents indicated that they would be talking about any of the topics of conversation by age group, sex, or rank of LSOA deprivation.

**Table 26: Mean differences in baseline and follow-up scores for how comfortable respondents indicated that they would be talking about different about end of life wishes and bereavement, excluding individuals with baseline scores of one or ten**

Topic of conversation	Sample size	Mean difference	P-value
Own end of life care	67	0.627	0.003
Own wishes for after your death	69	0.420	NS
Other's wishes for end of life care	77	0.182	NS
Other's wishes for after their death	77	0.052	NS
To comfort somebody who is bereaved	86	0.070	NS

There were no significant differences in change between baseline and follow-up by whether or not respondents reported having had the relevant conversations since the event.

### **6.3.7 Actions taken and changes made as a result of attending an event**

#### **6.3.7.1 Comparison of actions intended immediately after events with reported actions at follow-up**

Of the 133 respondents who provided complete data, 114 (86%) indicated immediately post-event that they intended to do something as a result of attending the event, and 80 (60%) indicated at follow-up that they had done something since the event as a result of attending it. Of the 114 who indicated post-event that they intended to take some action, 73 (64%) reported at follow-up that they had actually taken some action, and two reported in free text responses that they still planned to do something. In addition, seven of the 19 (37%) respondents who had not reported post-event plans to take some action, reported at follow-up that they had done something because of the event. The proportions were similar for 'Awareness-raising' presentations and 'How to' workshops. This data is shown in Table 28.

Respondents were asked post-event to describe things they intended to do, and at follow-up to describe things they did as a result of the event. This data was summarized thematically. Of the 73 respondents who reported both intending to take action immediately post-event and taking actions by follow-up, 30 (41%) reported intending to do and then actually doing something similar, 15 (21%)

reported doing part of what they intended and 28 (38%) reported intending to do and then doing completely different things. In total, including people who intended to do something but did not, people who did not intend to do something but did, and people who did something different to what they intended, 76 (57%) reported doing something different by follow-up to that which they had intended immediately post-event.

**Table 27: Numbers of follow-up survey respondents indicating an intention to take relevant action immediately post-event and reporting of having taken relevant action at follow-up**

			3-month follow-up		
Immediately After	Awareness -Raising		Made changes	Did not make changes	Total
		Plan changes	51 (65%)	28 (31%)	79 (87%)
		Don't plan changes	3	11 (12%)	12
		Total	54 (59%)	39 (43%)	91
	'How to'		Made changes	Did not make changes	Total
		Plan changes	22 (63%)	13 (33%)	35
		Don't plan changes	4 (10%)	1	5
		Total	26 (65%)	14	40
	Total		Made changes	Did not make changes	Total
		Plan changes	73 (55%)	41 (31%)	114 (86%)
		Don't plan changes	7 (5%)	12 (9%)	19 (14%)
		Total	80 (60%)	53 (40%)	133

### 6.3.7.2 Types of changes made

At follow-up, 80 of the 133 respondents who provided complete data (60%) indicated that they had either discussed their own end of life wishes or taken another action since the event and because of the event. This included 58 (43%) who talked about their own end of life wishes; 52 (39%) who did something else, and 30 (23%) who did both. This is shown in Table 29.

**Table 28: Number and percentage of respondents who reported having a conversation about their own end of life wishes or taking another action because of the event they attended**

Action taken	Number (%)
Discussed own end of life wishes	58/134 (43%)
Did something else	52/133 (39%)
Did both of the above	30/133 (23%)
<b>Did either of the above</b>	<b>80/133 (60%)</b>



A further 20 (15%) respondents indicated that they had talked about their own end of life wishes but would have done it anyway. Therefore 58 of 78 (74%) respondents who indicated they had talked about their own end of life wishes during the follow-up period indicated that it was because of the event they had attended.

By combining data from this question response with baseline and follow-up data on whether respondents had talked to close friends or family about their own end of life care wishes and wishes for after their death, it appeared that 12 of the 58 (21%, 95%CI 10.5% to 31.5%) had had these conversations for the first time, or 9% of the total sample.

Respondents were also asked to describe any actions which they had taken as a result of the event they attended, other than a conversation about their own end of life wishes. The data was summarized thematically. The following themes emerged:

- Talking about another person's end of life wishes
- Practical preparations for death
- Communicating differently
- Living differently
- Passing on the message

Six respondents indicated in free text response somewhere on the questionnaire that they had discussed somebody else's wishes.

The most frequently mentioned practical preparations for death were:

- Wills (14 respondents; 11 from Awareness raising presentations; 3 from 'How to' workshops) including one who had made a will, five who had made plans to make a will, three who had thought about making a will, and five who had changed or reviewed their will.
- Funerals (6 respondents, 2 from Awareness raising presentations; 4 from 'How to' workshops) including two who had planned their own funeral, two who had written down their funeral wishes and two who had researched funeral options.
- Power of attorney (4 respondents, 2 from Awareness raising presentations; 2 from 'How to' workshops) had either; arranged power of attorney (2), made plans to arrange power of attorney (1) or researched power of attorney (1).
- Four (2 from Awareness raising presentations; 2 from 'How to' workshops) made other practical preparations including organising finances (3),

decluttering their home (1) or changing their next of kin details on their HR file (1). Four (3 from Awareness raising presentations; 1 from a 'How to' workshop) had made more personal preparations, including three who had made a journal or record of family history, and one who had discussed an emotional will. One stated simply that they had thought about their wishes. Only one respondent reported making a living will and plans for end of life care; this individual also indicated that they were suffering a terminal illness.

Another relatively frequent theme was communicating differently about death (10 respondents; 2 from Awareness-raising presentations, 8 from 'How to' workshops); including being more open about death (3), being more confident or comfortable talking about death (3), talking more about death (2), listening better to others (2) and talking more about death. The difference in frequency between Awareness-raising presentations and 'How to' workshops reflects the difference in aims of the two types of event.

Six respondents (3 from Awareness-raising presentations, 3 from 'How to' workshops); stated they had lived life differently since the event; including four who stated they had lived life to the full or reviewed priorities, and two who had started working through their bucket list.

Four respondents (3 from Awareness-raising presentations, 1 from a 'How to' workshop) had arranged a similar or related information event, and two, both of whom attended Awareness-raising presentations, had discussed arranging an event. Seven (5 from Awareness-raising presentations, 2 from 'How to' workshops) stated that they had encouraged other people to talk more or prepare for death better. One was hoping to arrange another similar presentation in 2015.

There were three unique responses. One respondent stated that they had 'faced it', another had discussed leaving her body to medical science, and another had made an emotional will after suffering from a life-threatening heart attack, and found it helped her.

#### **6.3.8 What respondents remembered as most relevant to them**

In answer to a free-response question about what respondents found most relevant from the event, there was a wide range of replies, the themes of which were similar to those found immediately post events. The main difference between immediately

post-event and at follow-up was that fewer respondents mentioned themes relating to 'living well' or 'living life to the full'.

The most frequently mentioned theme was realising the need to talk about end of life wishes, including:

- Making their own wishes known (6)
- Finding out somebody else's wishes (4)
- Raising the issue with their families (2) and
- A general need for people to make their wishes known or talk to their family about their wishes (8).

Another theme was the need to plan and organise for end of life while still well (6). Other, similar, themes included the importance of being more open with family (3), overcoming reserve about death (1), planning and communicating (1), listening carefully (1), using humour in conversations (1) and encouraging friends to plan and talk (1). Three mentioned that they realised talking about death was easier than they thought, or not taboo.

A smaller number of participants stated the event made them realise the need for them to do something more practical, including making a will (3), reviewing or updating a will (2), planning a funeral or writing down funeral wishes (3), organising finances (1), or planning for the future (1).

Ideas that respondents mentioned as particularly useful or relevant included the emotional will (2), journal or family memory book (2), bucket list (2), ICE file or Life Book (2) and the MacMillan checklist (3). All of the respondents mentioning these ideas had attended Awareness-raising events, reflecting the content of these events. One respondent who attended a 'How to' workshop mentioned the idea of writing down wishes if the family would not discuss them.

Topics of information mentioned as particularly relevant included those relating to talking about death, and those relating to practical aspects of preparing for death. Information relating to talking about death included suggestions for how to approach conversations (8); how people talk about death and react to talking about it (4); the issues that hold people back from talking (1); how to support others (1); and change in societal attitudes towards death (1). The majority of respondents who mentioned information relating to talking about death (10/15) had attended a 'How to' workshop, reflecting the aims and content of these events. More practical aspects of

preparing for death included living wills/do not resuscitate (2), wills (1), and power of attorney (1).

Four respondents stated that the event had made them feel more confident to talk about death; all had attended 'How to' workshops. Eight stated that the event had made them think or helped them to clarify their thoughts, and three indicated that it made them reflect on something that had happened.

More generally, 15 respondents stated that they found the whole event relevant, interesting or useful, and seven stated that it had been useful in their professional capacity. One person mentioned that they enjoyed the style of the presentation and one person each mentioned the 'Bill United' video, discussions within the group (1) and the leaflets available (1).

Other responses included a topic for a University of the Third Age (U3A) discussion group (1); the fear and mystery of death (1); thought and empathy for people who are unwell (1); and wanting to leave a body to medical science (1).

Eighty-seven respondents commented on what they found particularly relevant both immediately post event and at follow-up. Of these, 46 commented on something completely different, 28 on something the same or very similar, and 13 gave comments which overlapped. This suggests that individuals may have found various aspects of the event relevant, and the priority given to each may change over time.

## **7. Questionnaire Survey: Discussion**

### **7.1 Summary of main findings**

#### **7.1.1 Characteristics of respondents and comparison with other surveys**

In the following section, the characteristics of the survey respondents are compared with the UK population as a whole, using data from the UK Census 2011, English Indices of Deprivation 2010, and various UK population surveys relating to attitudes about death and practice in preparing for death. The intention is to review how this survey adds to the current body of knowledge and to inform judgements of the generalisability of the results to other contexts.

Because of the difference in demographics between the study sample and the stratified random samples used in the population surveys, it was not possible to directly compare findings. In both the national surveys and the current study, most measures of attitude to death varied significantly by age group, but there was little variation between males and females. Comparisons between this and other surveys are therefore presented by age group.

#### **Demographics**

On average, respondents to this survey were older than the UK population as a whole (46% were over the age of 65 compared with approximately 22% of UK adults over the age of 20); were more likely to be female (76% compared with approximately 51% of UK adults over the age of 20); and they tended to live in areas with relatively lower levels of socio-economic deprivation, as reflected by the study area.

As almost three-quarters (74%) of people attending the CLWDW events during the research period were included in the survey, it can be assumed that the demographics reasonably reflected those of the population directly reached by the intervention. However, compared with the questionnaire sample, the actual population of people who attended CLWDW events may have included a slightly higher proportion of men and of people over the age of 75, as public health worker administering the questionnaires observed that these groups appeared to decline to participate in the research more frequently than others.

The demographics of the sample probably reflect the targeting of the events. The majority of Awareness-raising presentations were delivered to community groups

meeting during 'daytime' hours, effectively excluding most people who had full-time work or caring responsibilities. The majority of attendees were therefore retired or working part-time, resulting in a higher proportion of older people and females. In addition, many 'How to' workshops targeted people working in health and social care, or groups of informal carers; where females often outnumbered males.

Much, but not all, of the difference in socio-economic deprivation between the survey sample and England as a whole can be explained by the relatively low levels of deprivation in the study area compared with the rest of the UK. Further differences between the sample and study area are probably explained by the targeting of the intervention, as people living in deprived areas might tend to be younger and possibly less likely to be a member of a community group.

## Preparations for end of life

### Having a will

The proportion of respondents indicating that they had a will showed a steep increase by age group, following the same trend as national surveys, although, in most age groups, the proportion of participants who reported having a will was higher in this survey than in others. This is probably related to the relatively low levels of socio-economic deprivation in the study sample (see paragraph below). There might also have been some self-selection, if people with a will were more likely to attend the events than people without a will. This trend and comparison is shown in Table 30. In this survey, the majority of respondents without a will (74%) indicated that they were considering writing a will. This question was not asked in any of the national surveys, so it is unclear whether this is typical of the population as a whole.

**Table 29: Percentage of respondents who indicated that they had a will in this and other UK surveys, by age group**

Survey	Under 35	35 to 44	45 to 54	55 to 64	65 to 74	Over 75
Good Death 2006[116]	12%	33%	44%	50%	67%	
Dying Matters 2009[8]	6%	27%	40%	58%	75%	83%
Dying Matters 2012 [7]	8%	23%	37%	54%	77%	
Current Study	0%	33%	50%	67%	90%	95%

This survey used different indicators of relative affluence and deprivation to the national surveys, which all used socio-economic status based on type of work, generally considered a more precise indicator at the individual level. In all surveys, a larger proportion of participants in the more affluent AB group had a will than in the general less affluent and less educated DE group, shown in Table 31. The gradient was similar to that between people with postcodes within areas in the lowest quintile (78%) and the two highest deprivation quintiles in England (44%) in this study.

**Table 30: Percentage of respondents who indicated that they had a will in recent UK surveys, by socio-economic status**

Survey	*AB	*C1	*C2	*DE
Good Death 2006[116]	49%	34%	42%	31%
Dying Matters 2012 [7]	49%	39%	33%	25%

\*AB= higher & intermediate managerial, administrative, and professional occupations

\*C1= supervisory, clerical & junior managerial, administrative, professional occupations

\*C2= skilled manual occupations

\*DE= semi-skilled & unskilled manual occupations, unemployed and lowest grade occupations

The most feasible explanation for this gradient is that people with a higher socioeconomic status or living in a less deprived area tend to have more money and possessions, and so have both more to leave to others when they die, and more to spend on will writing advice. Verbal feedback from people attending an Awareness-raising presentation held in a highly deprived area before the survey began, was that making a will was not something that all of them thought they could afford to consider. It is also possible that people with higher levels of education and more social connections might feel more confident about writing a will, or might be more aware of the benefits of having a will.

### Talking about end of life wishes

Two national surveys asked “Have you ever talked about how you would like to die?”. The proportion of people who responded ‘yes’ increased with age. This survey asked a similar question, “Have you ever talked to close family or friends about your wishes about your care if you become unwell and at the end of your life?”. The responses to this survey showed a similar trend, although the proportion who reported ever having had these conversations was higher. This trend and comparison is shown in Table 32.

In the national surveys, there was no apparent pattern according to socio-economic status as to whether people had spoken about their end of life wishes. Similarly in this survey, there was no difference between respondents living in areas of low and high deprivation.

**Table 31: Percentage of respondents in this and other UK surveys who indicated that they had ever talked to somebody about their end of life care wishes, by age group**

Survey	Under 35	35 to 44	45 to 54	55 to 64	65 to 74	Over 75
Good Death 2006[116]	16%	31%	38%	44%	(51%)	
Dying Matters 2009[8]	25%	25%	27%	32%	36%	39%
Dying Matters 2012 [7]	22%	25%	32%	32%	(54%)	
Current Study	27%	39%	52%	55%	55%	60%

The 2012 ‘Dying Matters’ survey asked, “Have you ever told somebody whether you would like to be cremated or buried?”. This was similar to a question in this survey: “Have you ever talked with close family or friends about your wishes about what you would like to happen after your death?”. The proportion of people responding ‘yes’ to these questions was similar for similar age groups in both surveys, in both surveys rising steeply with age, although the in this survey there was a slight dip at ages 55 to 74. This trend and comparison is shown in Table 33.

**Table 32: Percentage of respondents in this and other UK surveys who indicated that they had ever talked to somebody about what they would like to happen after their death**

Survey	Under 35	35 to 44	45 to 54	55 to 64	65 to 74	Over 75
Dying Matters 2012 [7]	34%	39%	54%	63%	(69%)	
Thesis 2014	31%	45%	65%	64%	57%	74%

The 2012 ‘Dying Matters’ survey also asked: “Have you ever asked a family member about their end of life care wishes?”. This was similar to a question in the current study, “Have you ever talked with close family or friends about their wishes about their care if they became unwell and at the end of their life?”. The question in this survey was broader, as it also included conversations with close friends and with people who initiated the conversation themselves. The findings from the two surveys are shown in Table 34.



**Table 33: Percentage of respondents in this and another UK surveys who indicated that they had ever talked somebody else about that person's end of life care wishes**

	Under 35	35 to 44	45 to 54	55 to 64	65 to 74	Over 75
<b>Dying Matters 2012 [7]</b>	25%	25%	26%	26%	33%	
<b>Thesis 2014</b>	48%	57%	61%	57%	53%	42%

Compared with other surveys, a higher proportion in every age group reported having had this conversation, as might be expected from the broader question. The trend by age was towards higher percentages in the middle age group, while in the Dying Matters survey there is a small but steady increase by age group.

There could be several different explanations for this pattern by age. It could be a cohort effect, with older people less inclined than those in the middle age groups to talk about other people's end of life care wishes. However, this is difficult to imagine, as older respondents were also more likely to have talked about their own wishes, and questionnaire comments suggested that many conversations about end of life wishes were mutual. It could be a recall issue if perhaps, in middle age, some respondents had had these conversations with their parents and then later forget about it. It might have been a sample clustering effect. Some events were delivered to groups of health and social care staff, volunteers or informal carers, who might be expected to have more experience than average of discussing other people's end of life wishes. Respondents attending events targeted in that way made up 38% of the 45-54 age group compared with 20% in other age groups. However, this effect was small: fifty-nine percent of people attending events for professionals, volunteers or carers indicated that they had talked about another person's end of life wishes, compared with 52% of respondents attending other events.

#### How comfortable were people about talking about end of life wishes?

Three national surveys asked respondents how comfortable they felt about talking about death, with response options on a four or five point scale ranging from 'very comfortable' to 'very uncomfortable'. This was not directly comparable to any single question in the current survey. However, a roughly comparable measure was calculated, using a mean rating for how comfortable respondents said they felt about each of the five specific topics of conversation included on the questionnaire. The ten point scale was collapsed into five, and category labels assumed for these five score categories. In all four surveys, the majority of respondents of all ages said they were 'comfortable' talking about death, with respondents under the age of 35

least often reporting feeling comfortable, rising with age, and then falling slightly in the oldest age groups. This trend is shown in Table 35.

**Table 34: Proportion of respondents who indicated that they felt ‘comfortable’ talking about death in this and other UK surveys, by age group**

Survey	Under 35	35 to 44	45 to 54	55 to 64	65 to 74	Over 75
Good Death 2006 [116]	57%	65%	75%	63%	65%	
Dying Matters 2009 [8]	64%	73%	70%	74%	66%	63%
Dying Matters 2012 [7]	62%	66%	74%	79%	78%	
Current Study	71%	76%	78%	85%	89%	83%

In this survey, a similar trend was apparent for all five specific conversation topics. A minor exception was comforting somebody who had been bereaved, where the number of respondents who indicated that they felt comfortable increased consistently with age group. The consistency of this pattern across the different surveys and specific topics of conversation suggests that it is a genuine phenomenon in the UK population. It may be a cohort effect, a change across the life-course, a difference in perception of what ‘comfortable’ means and how to rate it, or a combination of any of these explanations.

Compared with the national surveys, a higher proportion of respondents, by age group, reported feeling comfortable talking about death. This may have been a result of the indicator being measured differently. It may also indicate some self-selection of respondents, with those who were less comfortable declining to attend events or to complete questionnaires.

In summary, due to the location of the intervention, its targeting, and self-selection of attendees, the participants in this research tended to be older, more often female, and suffered less socio-economic deprivation than the UK average. They also more often had a will, had talked to somebody close to them about their end of life wishes, and indicated that they felt comfortable talking about subjects relating to their own and other people’s end of life wishes.

Consistent with population surveys undertaken in the UK, the majority of respondents indicated that they felt comfortable talking about death. There was no apparent relationship between talking about end of life wishes and sex or level of deprivation, although there are clear differences by age, with older age groups most likely to have discussed end of life wishes. As with other surveys, respondents were

more likely to have made a will if they were older and indicators suggested that they were relatively affluent.

## **7.1.2 Effectiveness of the interventions**

### ***7.1.2.1 Acceptability and relevance to the target audience***

Both the Awareness-raising presentations and the 'How to' workshops were generally well-received. Positive comments included a number about the style of events themselves, including the sensitivity of delivery, the opportunity to discuss issues with other attendees, and the use of humour.

The events were generally rated as highly relevant. Seventy-nine percent, from both the Awareness-raising presentations and the 'How to' workshops, rated the event's relevance to them as 4 or 5 out of 5. This did not vary significantly by sex or by level of deprivation of postcode. Awareness-raising presentations received a significantly higher mean relevance score from respondents aged 45 to 74 than those aged under 45 or over 75. This might be because people within this age group, more often than others, felt that planning for end of life was relevant to them, but not something that they had done yet. It might also have been something to do with the style and delivery of the events, as the people who designed and delivered them were also mainly within this age group.

Respondents also mentioned a range of ideas, information and prompts that they found useful or relevant. These included practical preparations for the end of life, and also suggestions, such as the bucket list, for using awareness of mortality as a way to enjoy and appreciate life more fully. Many respondents mentioned more than one aspect of the event that was particularly relevant to them, and many of those who participated in the follow-up survey mentioned different aspects as being particularly relevant than they did immediately post-event. This suggests that attendees often took away more than one useful idea from the events, and that the relative importance of these ideas could change over time.

### ***7.1.2.2 Behaviour change***

Immediately following the events, 61% of respondents indicated that they planned to have a specific conversation with family or friends because of something they had heard at the event; including 69% of those who attended the 'How to' workshops, and 57% of those who attended the Awareness-raising presentations. The high

proportion following the 'How to' workshops might have been expected, as all attendees had actively chosen to attend an event that was advertised as helping people to have difficult conversations about end of life wishes. However, many attendees at Awareness-raising presentations were more passive, attending the presentation only as part of a community group meeting that they would normally attend at the same time. To achieve 57% of people intending to have a specific conversation because of the event therefore seems a particularly impressive achievement. In line with the aims of the programme, the most frequently reported conversation subject was the respondents' own end of life or funeral wishes.

The results of the follow-up survey suggest that many respondents (59%) followed through on their intentions, while some (28%) who did not report such an intention had actually talked with somebody about their end of life wishes at follow-up, and attributed this to the intervention. Forty-nine percent of responders to the follow-up survey indicated that they had talked with close family or friends about their own or another person's end of life wishes because of the event, compared with 68% who had reported immediate post-event that they planned such a discussion. This suggests that this intervention was successful in encouraging people to take action over the following three months, rather than just think about it.

The results also suggest that the intervention was equally effective in encouraging people to talk about their end of life wishes whether or not they had ever discussed the subject before. The respondents who reported that they had discussed their end of life wishes because of the intervention included 17/32 (53%) of those who indicated at baseline that they had not previously talked about their end of life wishes and 42/109 (39%) who indicated at baseline that they had previously discussed their own end of life wishes. The numbers were small and there was no significant difference between these two groups.

Fifty-five percent of respondents, including 52% of those who attended the 'Awareness-raising' presentations and 62% of those who attended 'How to' workshops, indicated that they planned a change or action other than a specific conversation. The most frequently planned actions were practical preparations, most often writing or updating wills or planning a funeral. Emotional preparations were also frequently stated, including emotional wills and journals of family or personal history. Others planned to live life to the full, make a bucket list, communicate differently about death, or support other people better. Only three

respondents mentioned planning for end of life care, suggesting that this was not an issue of great importance to the majority of people.

At follow-up, 33% reported that, because of the event, they had done something other than talking to somebody. Reported actions were mainly practical preparations rather than emotional preparations or living life differently. It was not possible to determine whether respondents were more likely to act on intentions to make practical preparations than emotional preparations, or just more likely to report practical preparations than emotional preparations, because they are more tangible.

Only two respondents reported a change in will status because of the event. Of those who had a will at baseline (98), one had changed their will because of the event, although two were in the process of organising changes and four were thinking about making changes. Of those who did not have a will at baseline (34 of those who completed follow-up questionnaires), one had made a will because of the event; three were in the process of organising a will, and two had made a definitely decision to make a will. Therefore 6/34 (18%) had made some change towards making a will. It might be that the process between starting to think about making a will to actually making a will often takes longer than three months. A longer follow-up period might identify whether, in fact, the events did increase the numbers of people making a will, but would have been impractical due to increases in loss to follow-up and diminished recall of participants. It might also be that different, more practical interventions are needed to increase take-up of wills.

At follow-up, 60% reported that they had done something because of the event, compared with 86% who reported immediately post-event that they intended to do something. In total, 60% of those indicating immediately post-event that they intended to take some relevant action, and 37% of those not indicating this intention, reported taking some action by follow-up. Of those who reported both intention to and actually taking action, 38% reported doing something completely different to what they had intended. In total, only around 43% reported doing by follow-up either fully or partly what they had intended immediately post-event. This suggests that intentions can change quite considerably over a relatively short period of time. It highlights the need, when assessing the effect of one-off interventions, for medium-term follow-up beyond the event.

### ***7.1.2.3 Change in how comfortable respondents felt about talking about death***

Overall, there was no apparent change between baseline and follow-up in how comfortable respondents indicated they felt about talking with close family and friends on any of the five subjects relating to end of life wishes and bereavement. The majority of respondents gave a very similar score at both time points; 77% of them within one point either side on a ten point scale. However, baseline scores were high (mean 8.60 for all five topics of conversation combined) and the most frequent baseline score was 10, so there was limited scope for increase. When respondents with baseline scores of 10 or 1, which could only change in one direction, were excluded from the analysis, there was a small but significant mean increase in score for talking about own end of life care (0.62,  $P=0.003$ ) and a close to significant increase for talking about own wishes for after death (0.42,  $p=0.055$ ), but no significant changes for other topics. There was no significant difference in change between baseline and follow-up between respondents who reported having relevant conversations or not because of the event.

These results suggest that there might be some association between how comfortable people feel about talking about end of life wishes and whether they have been exposed to some discussion of these issues, such as these events, although this does not seem to play an important role in how the interventions worked. The direction of causation may have been either way or both; becoming more comfortable with the idea of talking about end of life might help facilitate those discussions, and experience of having those discussions might make people feel more comfortable talking about the subject.

### **7.1.3 Reach of the intervention**

The survey sample was predominantly female and almost half were over the age of 65; it appears that the intervention was less successful at reaching men and younger people who might have benefitted from it. However, there is evidence within the findings that the messages reached many men and younger people indirectly. The majority of respondents were married or living with a partner; and the most frequently reported response to the events was to plan a conversation with somebody close, most often a spouse. It is therefore very likely that many female attendees later discussed aspects of the presentations and workshops with their husbands and partners, and the messages were informally disseminated to men in

this way. In fact, 27 female respondents reported that they planned to talk to their husband about something following the event; and 45 reported that they intended to talk to their child or children (not all of whom would be males).

There is also evidence that a few individuals attending the interventions went on to actively promote the messages of the events. At follow-up, four respondents reported that they had organised similar or related events for other groups, and another that she was hoping to organise a similar event in 2015. Seven respondents reported that they had encouraged other people to talk more about or prepare better for death.

By encouraging discussion with others, the interventions could be acting like 'seeds', spreading ideas within the population. The population eventually benefitting from the intervention could therefore be far larger than the number of people attending.

People of different age groups seemed to respond slightly differently to the events. Respondents aged 45 to 74 reported taking some action because of the events more frequently than older and younger groups. Respondents aged 75 or over reported taking action less often than all other age groups. The 45 to 74 age group, which appeared to respond most positively to intervention, also comprised the majority of respondents (327/497, 66%), suggesting that events were fairly well targeted in terms of age. Within this age group, participation was skewed towards the older age groups (71 respondents were aged 45 to 54 compared with 109 aged 55 to 64 and 147 aged 65 to 74). It could be argued that people aged 65 to 74 are at greater risk of death in the near future than younger people, and that therefore targeting this age group is an effective use of resources. The intervention was also effective, although to a lesser extent, for people under the age of 45 and over the age of 75. The relative effectiveness of the interventions in different age groups reflects the difference in reported relevancy by these same age groups. It may be that slightly different interventions would be more relevant and possibly more effective in encouraging change for audiences comprising mainly people under the age of 45 or over the age of 75.

## 7.2 Methodology and limitations

A primary objective of this study was to measure changes in attitudes and behaviour between before and after the CLWDW public health events, to assess the effectiveness of the events in encouraging attendees to consider their end of life preferences and discuss them with the people closest to them. In the positivist tradition, the study was designed to be as objective as possible, and the analysis and interpretation of the results assumed objectivity. However, various practical limitations meant that, in reality, the study is subject to a range of biases which will have, in unknown ways, affected the measured outcomes.

The most obvious type of bias, for which there was definite evidence in this study, was non-response bias. Compared with non-responders, participants who completed follow-up had, at baseline, rated the event as more relevant and more often reported an intention to do something as a result of the intervention. There is therefore good reason to suppose that responders also more frequently took action as a result of the intervention. As a result of this bias, estimates of effectiveness, in terms of percentages of participants reporting taking some relevant action because of the events, were probably over-estimates. Response bias might have been reduced by increasing the follow-up rate. However, scope to do this was limited by the level of interest there was in participating, and the ethical and practical need to obtain written permission and contact details to contact participants. There were some comments from participants that they did not want to give out their contact details due to fear of receiving 'junk mail'. With hindsight it may have increased the response rate to include, within the information for participants, the information that their details would not be passed to others. Another possibility for increasing follow-up participation might have been an incentive, such as entry into a free prize draw. It was decided not to go down this route due to concern that it might appear to trivialise a serious subject or decrease the quality of the data received.

Another potential source of bias was attribution bias. Unlike experimental study designs, which are considered in positivist research to be the most objective way to measure the effect of an intervention, the study had no control group that was not exposed to the intervention. If an experimental design had been used, the proportion of participants reporting the relevant outcomes could have been compared between intervention and control groups, and the difference between the two groups taken as a measure of the effect of the intervention. This would have removed the need to ask participants whether their intentions and actions resulted



from their attendance at the events. Intentions and behaviour are influenced in complex ways by multiple factors, so respondents' reports as to whether a specific intervention was the deciding factor cannot be classed as a truly objective measure. Attribution bias might have occurred if respondents who took a specific action attributed this to their attendance at the event, when in reality they would have done it anyway, or vice versa, if the mistaken attribution occurs more in one direction than the other. There is no way of identifying the presence of, direction of, or magnitude of attribution bias in this study, it is only possible to say that it might be present.

Recall bias is another potential issue in any study which relies on self-reports of behaviour. In this study, recall of having had a specific conversation, or taken a specific action, might have been influenced by level of awareness of the issue, which might be increased (and was intended to be increased) by attending an event. The most likely direction of this bias is that people who attended events might have recalled more of the relevant actions they took than they would have done if they had not attended the event. This would have caused the effect of the interventions to be over-estimated. There was some evidence in this study that recall differed before and after events. In comparison of self-reports, pre-intervention and at follow-up, of whether participants had ever had specific conversations, a small number of participants changed their response from having had the conversation, to not having had the conversation, which is obviously impossible. There was no evidence that these mistakes of recall introduced systematic bias; but there is conversely no evidence that they did not. However, because the follow-up period was relatively short, and preparations for end of life are probably not an 'everyday' occurrence (and might therefore be fairly memorable), it seems probable that any effect of recall bias was small. An experimental study with a control group would have been equally as affected by recall bias as the study design used.

Another limitation was that the study relied on self-reports, which can be subject to social desirability bias, where participants sometimes give a particular response which they think the researcher wants to hear, rather than what they are really thinking. This tends to be less apparent when, as in this study, questionnaires are self-completed. However, it might still have been a minor influence, as baseline and post questionnaires were completed in the presence of others, and, for those who provided contact details for follow-up, responses were, of necessity, not made anonymously.

The study could also have been affected by recruitment bias, if people who chose to participate in the study from the start differed systematically from those who chose not to participate. For example, it is possible that the group which chose not to participate were less interested in the subject of the intervention (and the attached research) than the group that participated, and that, as a result, the events had less impact the group that did not participate in the research. Recruitment bias was minimised in this study by maximising the recruitment rate (74%), achieved by inviting all attendees to participate, and making participation as easy as possible by using a brief and simple questionnaire, and providing pens, clipboards, and assistance where needed. An experimental design might actually have increased recruitment bias, if participants in the intervention and control groups differed in systematic ways.

Using a control group might have introduced attrition bias, if there was a systematic difference between the intervention and control groups in characteristics of participants who completed follow-up or were lost to follow-up. This is similar to non-response bias and might occur, for example, if participants who attended events became more interested in the study and hence more often completed follow up than those who had not attended.

Another study design which might have been considered is something similar to a case-control study. With a modified case-control design, people who attended events might be compared with matched controls who had similar demographic characteristics but had not attended events. Like an experimental design with a control group, attribution bias could be eliminated by removing the need to ask participants whether actions they had taken were a result of their attendance at the event. However, this design might have even more problems. If a reliable estimate of effect was to be calculated, the study outcomes would need to be precisely defined in advance, whereas in reality, because the intervention was complex and innovative, there was not one single expected outcome. It would also require advertising for and recruiting control subjects, which would be labour-intensive, expensive and without guaranteed success. Because the intervention was new, it was not possible to estimate the number of attendees who would report the desired outcomes, and hence it would be uncertain whether a sample size sufficient to power the study could be obtained. The controls could introduce bias if they differed in a systematic way to the general population and those who attended events. The information given to controls about the study might act as an intervention in itself,

prompting people to do things which they might not have otherwise. A case-control study would also not eliminate other sources of bias, including attrition bias, recall bias and social desirability bias.

In summary, although the non-experimental design of this study used some measures which may not be completely objective, and was subject to various methodological biases, using an experimental design could not have completely eliminated these problems, and would probably have introduced its own. An experimental study would, in any case, have impractical and expensive, as a suitable control group would be difficult to recruit and follow up. The method used, despite its inherent weaknesses in objectivity, was probably the most appropriate for the intervention and circumstances.

The questionnaire itself, although designed carefully to elicit responses that were as objective as possible, also had weaknesses. Due to the context it was used in, it needed to be quick and easy to complete, and to appear quick and easy to complete. There was therefore limited potential to include additional questions for cross-checking, which might have identified if the precise wording of questions was influencing the responses in a particular direction, and served as a check on the accuracy of responses. Due to time and resource issues, piloting was limited to a small group of individuals who were already involved with the hospice or CLWDW programme. Therefore there was limited input into the wording of questions and response categories and how they might be understood by respondents. Within the brief questionnaire used, there were some instances where responses to different questions were inconsistent with one another; however these were rare enough not to significantly affect the results.

Another possibility is that the questionnaire itself acted as an intervention, in making people think more about preparations for end of life, and talking about death. In fact, one respondent wrote as a comment on a follow-up questionnaire *“your questionnaire has prompted me...”*. It is not possible to eliminate this effect in research, except with the use of a control group which received the same questionnaire. However, it may not be very important, as is it standard practice to use questionnaires to evaluate an event, including asking participants what changes they intend to make. The only difference was that the research questionnaire was more detailed than those usually used for evaluation purposes, and that there was the potential for follow-up.

Data collection relied, for certain details, on 'free-text' responses to open questions. Data collected in this way may be less comprehensive and accurate than similar data collected via closed response questions, as some participants may not take the time to complete open answers, and responses received may be difficult to neatly categorise into themes. For example, it was not always possible to identify whether a respondent was referring to something they found interesting about the event or something they intended to do as a result of it. However, closed response questions also have their drawbacks, in that they force responses into categories which might not accurately reflect what the respondent wishes to convey. In the case of this study, completely closed questions would have been inappropriate because this was a new intervention, with broad objectives, where the expected outcomes were not defined in detail and difficult to anticipate. Open questions, despite their weaknesses, were required to identify these detailed outcomes, and to roughly quantify their occurrence.

An important issue for this study was that it aimed to quantify attitudes to talking about death, dying and bereavement, conceptualised as 'how comfortable?' people were with the idea of having these conversations themselves, in the absence of a body of research into how attitudes relate to practice. Similar questions have been asked as part of various other surveys about attitudes to death and dying [7, 8, 116, 117] and it therefore served a useful purpose in comparing the results of this survey to others. However, the idea that people may not talk about death because it makes them feel uncomfortable, and that discussions can be facilitated by making people feel more comfortable, did not arise from research with members of the public but from the popular press, academics and policy-makers. Whether they felt comfortable talking about death might not have been the most relevant question for assessing individual attitudinal barriers to discussing the subject. In the free text responses to questions about what was useful about the events, there were many more references to feeling more 'confident' after attending an event than to feeling more 'comfortable'. This suggests that feelings of discomfort may not be less relevant to conversations about end of life wishes than lack of confidence.

Some of the data collected via the questionnaires was not used formally in the analysis. This was the data elicited from free-text questions at the end of the questionnaire, inviting comments about the events and about the subject in general. It was originally intended that this data would be analysed semi-qualitatively and presented as findings by theme. However, it was decided that including this data did not add sufficiently to overall findings of the thesis to justify their inclusion. The data

was however, summarised by the researcher and used to inform the qualitative analysis, and might also be included in some way in later papers specifically about the interventions.

Even within the context of the unavoidable biases and weaknesses of the research design, the findings are striking. Sixty percent of respondents who completed follow-up said that they had taken some action because of the event. The study results are almost certainly affected by non-response bias, but other biases probably had a much smaller influence, if any. Assuming no other bias, the worst case scenario, assuming that, at follow-up, none of the non-responders had taken any action because of the intervention, was that of the 676 people attending, 80 had taken some action (12%, 95% CI 9.6% to 14.5%). This extreme and unlikely worst case scenario still seems a considerable response to a low-intensity intervention delivered primarily to members of community groups who had expressed no particular interest in the subject.

### **7.3 Conclusions on the effectiveness of the interventions**

This research strand forms a complete study in its own right and the results would be of interest to anybody considering developing or commissioning public health interventions to normalise and encourage discussions about end of life wishes among people who are well. The results suggest that a brief, well-designed, interactive presentation, designed to raise awareness and signpost to further information, can be viewed as relevant by those who attend, and be successful in prompting them to consider their end of life preferences and discuss them with the people closest to them. Presentations or workshops which provide ideas and examples of how to open end of life discussions can increase recipients' confidence to have these conversations. At least some of the people who attended these presentations and workshops went on to talk with friends and family about what they heard, and a few organised similar events, thus increasing their reach. The interventions tested in this study involved a relatively affluent population, the majority of who were aged over 45, and had the greatest impact on people aged between 45 and 74. Interventions aimed at younger or older audiences, or deprived communities, may benefit from some adaption to increase their relevance.

## **7.4 How the qualitative research strand will build on the findings of the quantitative**

This quantitative research strand has demonstrated that targeted health promotion activities can prompt members of the public to prepare for the end of their life, and to discuss their preferences with the people closest to them. It has also begun to suggest how they might have worked; a number of participants made short written comments about the events 'making them realise' the benefit of something; 'prompting' them to do something; or increasing their confidence. It has shown that the potential of such events to make people feel more comfortable about talking about death is probably limited, and that its impacts are, in any case, probably mostly independent of this effect. The qualitative study, by describing in greater depth the context in which the events were delivered and the experience and reactions of some of people attending the events, might be able to explain these mechanisms in greater detail, and give some insight into the degree to which the effects might have been context-specific or potentially transferable to other settings.

The quantitative study has also confirmed the findings of other population surveys, which showed that the majority of people report feeling comfortable talking about death [7, 8, 116], including their own end of life wishes [117] and yet many do not have these discussions. It also identified that many people who do not have a will report that they are considering making a will. The qualitative strand might be able to go some way towards explaining these patterns, and identifying the true barriers to these preparations and discussion, building on research by other authors, which has tended to focus on elderly or sick populations.

The collective experience of people working with people who are dying, and theories of prominent academics [5, 20, 141, 186], suggest that increasing discussion about end of life preferences should be beneficial to population wellbeing. Presumably, many participants in the quantitative study considered the benefits and drawbacks of the activities and considered the effort worthwhile. However, there is still little research-based knowledge of the potential benefits, drawbacks and limitations of discussing end of life preparations and preferences, or on the views of the public about these matters. The qualitative study might begin to build this knowledge, so that the potential contribution that considering and discussing end of life preferences could make to population wellbeing might be better understood.

The qualitative strand also aims to widen the scope of the research to areas, as described in the Methodology Chapter 4.

## 8. Interview Study: Results

This section begins with a description of the interview study participants, followed by the findings of the study, presented by theme and sub-theme.

### 8.1 Characteristics of the participants

Twenty-eight interviews were conducted, including 25 interviews with one participant each, and three double interviews with two participants together. The three double interviews included two with a husband and wife together, and one with two who both worked together and were friends outside of work.

The sample included 18 women and 13 men, ranging in age from 30 to 85, with the largest number being in their 50s and 60s. Table 36 shows the number of participants by ten-year age band.

**Table 35: Number of interview participants by age band**

Age Group	Number
30 to 39	4
40 to 49	2
50 to 59	11
60 to 69	8
70 to 79	4
80 to 89	2

The participants had various interests in end of life issues. Ten were either a member of staff or volunteer either in a hospice or a public health end of life programme. A further two were lay readers for the Church of England, and thus had a role in bereavement support and funerals. Nine either did voluntary work with the church, or were active church-goers and talked about their faith as something very important to them. Four had caring responsibilities for somebody with dementia, and four were social workers in adult care services. One had been diagnosed with a life-limiting illness, although was currently well, and three had recently been treated for cancer but were in remission. Four talked about an experience where they were very close to death but recovered.

Table 37 shows some of the main characteristics of the participants, in the order that the interviews were conducted, and their pseudonyms.



**Table 36: Characteristics of the qualitative interview study participants**

Interview	Age	Sex	Profession	Volunteer roles	Family	Notes	Pseudonym
1	50s	F	Nursing Sister at hospice		Widowed. Adult son. Young grand-daughter.		Susan
2	64	F	Retired	Hospice greeter, CLWDW event support person, bereavement support group facilitator	Widowed. Adult son. Adult grandson.	Cares for elderly mother with dementia	Margaret
3	40s	F	Self-employed end of life planning facilitator	Facilitator on 'Conversations for Life' and various projects with people living with a life-limiting illness	Married. Teenage daughter.		Julie
4	65	F	Retired director of a haberdashery company	Bingo caller in an old people's home	Single. No children.	Diagnosed with a terminal illness, but well	Christine
5	74	F	Retired travelling sales representative	CLWDW event support person	Divorced and re-married. 2 daughters, 1 step-daughter, 9 grandchildren, 3 great grandchildren		Patricia
6	65	F	Retired counsellor, specialised in HIV		Married. Adult son.	Another son died suddenly aged 19.	Ann
7	50	F	Complimentary therapist at hospice		Married. 3 young adult children at home		Karen
8	55	F	Retired school cook		Married. Adult son and daughter. 2 young grandchildren.	Has Parkinson's. Husband is a counsellor at a hospice	Jacqueline
9	72	M	Retired hairdresser (including work in hospitals)	Red cross first aid cover	Married. 3 adult children. 5 young grand-daughters	Visits sick people on his estate	John

10	60s	M	Retired vicar	Chaplain at a hospice	Married. Daughter and grand-daughter.	Had cancer himself	David
11	50s	F	Social worker: disability		Married. 4 adult children, 3 step daughters. 5 grandchildren, 6 step-grandchildren, 2 step great grandchildren	Husband is a Methodist lay preacher. Her father was too.	Deborah
12	40s or 50s	F	Social worker: shared lives		Widowed. Children (don't know number or ages)	Cared for partner who died of lung cancer. Was once close to death but recovered.	Jane
13	70	F	Retired	Lay reader in Church of England	Married. Adult children.	Has multiple sclerosis. Was once close to death but recovered.	Mary
14	58	F	Secondary school teacher (RE and textiles)	Church work	Married. Don't know about children, not mentioned	Active in local church. Visits local people who are sick or bereaved. Husband in remission from aggressive cancer.	Janet
	58	M	Practitioner paramedic (rapid response car)				Stephen
15	60s	M	Retired electronic engineer	Church work in local old people's homes. Runs small charity in Africa.	Married. Adult children.		Michael
	60s	F	Full-time Home-maker				Linda
16	59	M	Steward at Man United (previously worked as a carer)		Single. No children.	Cares for elderly mother.	David
17	50s	M	Retired secondary school teacher.	Lay reader in Church of England. School governor.	Married. Adult children.	Retired early due to stroke. Almost died of it. Left with chronic pain.	Andrew
18	69	M	Retired; various jobs (RAF, Ford, Court Usher)	Fund raising and local work with Rotary Club	Married. 2 adult daughters and 4 grand-daughters	Was once close to death but recovered.	Robert

19	37	F	MacMillan Physiotherapist		Married. Twin sons aged 5.	Active in local church.	Sarah
20	32	F	Fund-raiser at hospice		Married. No children		Laura
21	75	F	Retired music teacher		Married. Adult son and daughter	Carer for husband with Parkinson's and dementia, and brother with learning disabilities	Joan
22	50s	F	Social worker: shared lives		Widowed. Adult son and daughter		Helen
23	50s	F	Social worker: shared lives		Married. 3 children, 3 adult, one in 6 <sup>th</sup> form		Gillian
24	30	M	Co-directors of a theatre workshop company		Married, no children	Churchgoer who talked about his Christian faith	Christopher
	30	M			Married, no children		James
25	85	M	Retired NHS administrator		Married, 3 adult children, 4 grandchildren		George
26	50s	M	Counsellor in a hospice		Lives with partner, no children		Peter
27	69	M	Retired – worked at Rolls Royce		Lives with partner, no children	Carer for partner with dementia	Tony
28	80	M	Actor and author		Single, no children	Had experience of being close to death.	William

## 8.2 Findings

This section is divided into four sub-sections. The first describes the participants' own views of death, and the context for talking about death. It describes their and other's feelings about planning for, reacting to, and talking about death, and the benefits and difficulties of these activities and discussions. The next section looks at identified barriers to end of life preparation and discussion, and how they could be overcome. The final two sections describe participants' ideas for relevant public health activities, and their views of the CLWDW programme.

### 8.2.1 Views about death

Participants all described how death had affected or would affect them in some way. Death was considered an important issue, although the nature of the issue varied with age and circumstance.

The four participants under the age of 40 were concerned about coping with bereavement and supporting friends and family who were dying or bereaved, illustrated by the quote below. They were less concerned about their own deaths, although all four wished to make some preparations in case of unexpected death.

*"... I don't see death affecting me as an individual, I mean one day I'll die, I know that, but death has affected me like loads over, over the last kind of decade... I've had numerous experiences of it, from best mates taking their own lives, to kind of, er, like, you know, mates, going to mate's mum's funerals, where I didn't really know their mum, but my mum was friends, or my granddad's funeral.."*

*James, age 30*

Participants in middle age (between the ages of 45 to 65) were often concerned about caring for elderly parents, what they would need to do when their parents died, and starting to think about what might happen if they or their partner became ill or died, especially in relation to any children they had. The quote below illustrates one participant's concerns.

*"...I would like to get my things sorted.....we've three children and we've never made a will...I said, "We really should be sorting it out.....what if anything happens?"*

*Karen, age 50*

Participants in later life were often concerned about their own end of life care and death, and those of partners, friends and family members. Some were carers for partners and spouses, and were concerned about the potential effect of their own death on the other. The quote below illustrates an older participant's concerns about caring and bereavement.

*... "...that's the great worry, ending up as carer for of somebody dying. I mean it just happened to (neighbour) and we watched it happen over two years, er. I mean, talk about being at a loss..."*

*Robert, age 69*

Older participants tended to contemplate their own death with sadness for the people they would be separated from, for example grandchildren who they would not see growing up, or a partner who might be left alone. However, a few participants were not worried about the idea of dying at all. One, who was a volunteer chaplain in a hospice, observed the range of responses that hospice inpatients had towards dying, shown in the quote below.

*...I guess the most important part of their process is, to die...and that is sometimes, awful, sometimes it is frightening, sometimes it's good, sometimes it seem to be, for some, just ignored....a wide range."*

*David, age 60+*

Participants usually contemplated and experienced the deaths of family members and close friends with great sadness. However, occasionally bereavements were felt as a relief, for example, where caring responsibilities had been difficult or relationships were poor, as the following quote illustrates.

*....."with my mother, she was such hard work and there was doctors and hospitals and wheelchairs and whinging and all of that sort of thing, which you get fed up with, so as I said, when she did die it was a relief to be honest..."*

*Joan, age 75*

Participants talked about various fears and anxieties associated with death, although often not as applying to themselves, but to other people that they knew or knew of. These fears were thought to make it more difficult to talk about death, and are therefore described in more detail within the 'Barriers' section of this chapter.

### 8.2.2 Talking about death

The majority of participants considered it important and natural to talk about death, and generally thought that it would be beneficial if people talked more about death. A frequent comment was that death was 'part of life', although some qualified this, as some deaths were more difficult to think of in this way than others. This is illustrated in quote below:

*....".... death is part of life.....so it's not a huge disaster.....it is a huge disaster, if, if the death is of a child.....or a sudden death from violence.....it's not a disaster in old age, it's just the way life is"*

*Mary, age 70*

Interestingly, one participant stated that she had never talked about death, did not want to talk about death, and did not want to upset her daughter by talking about her death, yet also described conversations that she had had with her daughter about her wishes for end of life medical treatment:

*.."(I) never talked about death to anybody, and, as I said, I talked about power of attorney with my daughter, and, you know, said I don't want to be kept alive and that, but I think it, she would find it very upsetting if I talked about death, about my death to her..."*

*Joan, age 75*

Many participants commented that they were unusually open and comfortable talking about death, and offered explanation for their own relative openness. Reasons included their basic nature, roles they had, previous life experiences, religious faith, or a combination of the three. The quote below illustrates this general view of self and others.

*..."...I don't find it a problem talking about dying, it's the people outside that find it difficult.....I don't think church people have a problem..."*

*Linda, 60+*

Many participants also commented that it would not be right to spend a long time thinking about and talking about death, as it was important to 'get on with life'. The following quote illustrates one participant's perception of the majority view.

*.....I think the vast majority of the population just want to get on with their lives and they don't, they don't spend a lot of time thinking about death and so on, it just happens...*

*Mary, age 70*

In summary there was general consensus that talking about death was important. Although the participants themselves were comfortable with the subject, they perceived that many other people were much less comfortable.

### **8.2.3 End of life preparation and discussion**

#### ***8.2.3.4 Importance and function***

All participants considered it important that people prepare in some way for their own death, even when death was probably far in the future. Most described conversations that they had had with somebody close to them about their own or the other person's wishes. These conversations were most often between spouses or partners, or between parents and adult children, but sometimes included other family members or close friends. The most common plans and conversations reported were around wills and inheritance, funeral wishes, and end of life care. Power of attorney, organ donation, and various emotional preparations were also mentioned. Discussions and preparations were considered to be of benefit to everybody involved, although most were more for those who would be bereaved rather than the dying. One participant summarized this view as:

*..."...if you know you are coming to the end of your life, and the people you love and care about know what your wishes are, then that's going to make everybody more peaceful with the transition..."*

*Laura, age 32*

Participants expressed the view, often illustrated by experience, that talking about end of life wishes might help to prepare the family for bereavement and prevent 'complications' and family conflicts around the time of and after death. The following quotes illustrate this theme, which is expanded on later in the section.

*..."The more you talk about it, I think the easier it becomes for everybody to accept it..."*

*Jacqueline, age 55*

*...”..It can save a lot of complications, a lot of wasted money and a lot of probably nastiness that goes on in families..”*

*John, age 72*

Talking about end of life wishes was also considered beneficial to the person whose death was being discussed, in helping to get wishes met, putting minds at ease in regards to the ‘having their affairs in order’, and deciding what was important in life as well as death; although this tended to be emphasised less than the benefit to the bereaved. Despite the perceived benefits, participants also recognised that talking about death in advance did not always lessen the pain of bereavement when it happened, as illustrated in the quote below:

*..”.....my father.....wasn’t afraid of talking about death.....but when my mother died, he went berserk...they phoned my dad up and they said, well, they couldn’t really do anything so they’d just keep her comfortable. And my dad rang me and he was out of his mind, and I said, “Dad, Dad, Dad”, I said, “You knew, didn’t you, you knew”.....and he, very bleakly, he said, “Yes but you always cling on that that one bit of hope, don’t you”.....”*

*Mary, age 70*

#### **8.2.3.5 The best times to talk about end of life wishes**

Most participants had the view that the best time to talk about end of life wishes and start preparing for death was usually when still well. It was thought that discussions could be easier at this point rather than after diagnosis of life-threatening or life-limiting illness. This is elaborated on later in this section. Participants also commented that in sudden death; incapacity such as stroke; or dementia or serious illness which quickly progressed, preparations and discussions while well were essential. The quote below illustrates the experience of a participant who was a paramedic on a rapid response ambulance, and saw the regret of people who did not know their deceased spouse’s funeral wishes.

*.....”I sign many interim death certificates, and, on many occasions....it’s just happened ..... and they say to me, “Now, I don’t know what he wants, I don’t know what arrangement they want...”, and “Does he want to be cremated or buried?”.....”*

*Stephen, age 58*



Some participants commented that, despite the potential benefits, it might be unrealistic to expect most young adults to discuss wishes, unless an event had occurred which would highlight future mortality. One participant suggested it might be difficult for most people to seriously contemplate their own death until they are in their forties. Another suggested it might be as old as the sixties. The decision to start thinking about end of life wishes often followed some sort of external 'prompt', such as a birth, death, marriage or illness. This prompt could also be something indirect, such as a news item or a conversation. In the quote below, a participant describes how the deaths of friends prompted her to start thinking about making a will.

*...."....from personal experience of losing friends quite suddenly .....I've actually started to think, "Oh hang on, perhaps we need to know a little bit more about making a will.." .....*

*Laura, age 32*

For some, talking about end of life plans was easier in old age, when it seemed more relevant. However, if it was left too late, it could become more difficult due to the emotional impact of being more 'real'. The following two quotes illustrate these two slightly different views.

*....."....people don't talk a lot about death, until it's likely to be happening.....and then they will talk about death.....they're quite happy..... to talk about the practicalities of what you need to do.."*

*Andrew, 50+*

*..."When you're young, it's not, it doesn't matter, you don't need to talk about, because it's years away, but then as you get older you don't want to talk about it do you? Because it is a reality.."*

*Stephen, age 58*

People who were aware of having a life-limiting or life-threatening illness often wished to discuss end of life wishes, to ensure that affairs were in order and to prepare loved ones. However, conversations could be more difficult at this stage, especially if the person had not previously talked about this subject. During potentially curative treatment for a life-threatening illness, talking about end of life wishes might not be helpful, as individuals try to remain optimistic and concentrate

on recovery. The same could sometimes be true of people with a terminal illness, especially if they had not fully understood or accepted that they were dying. This could be difficult for the people closest to them. The quote below illustrates this theme.

*....."I had quite aggressive cancer and I'm fine, got the all clear, I just didn't want to talk about it.....you just think you're going a get better....., to accept the fact that you're not going to get better...is, really a, sort of like...a full stop..... Well I wouldn't accept that, when I was ill, I was, I was, I knew I was ill, so, but, yeh, better, talked about it since....."*

*Stephen, age 58*

These barriers may have been linked with the need to stay positive and the common idea that remaining positive could increase chances of survival, as described in the quote below. Another participant commented on the unhelpful language of 'fighting' illnesses such as cancer.

*..."...he had really advanced stomach cancer...but he wasn't positive.....  
"I'm going a die, I'm going a die", and he'd just gone into this decline.....another member of the golf club, he was told the same.....he had chemo treatment.....and a month later he was playing golf again  
..... he doesn't want to do with that dying thing..."*

*Robert, age 69*

In case of terminal illness, there were also other factors making it more difficult to discuss end of life issues. Both the person who is ill and those close to them might be in an emotional state, there are many other things to think about, and the person will probably feel tired and ill. In the quote below, a participant talks about a friend who has a terminal illness.

*...."....he's terminal.... but he won't discuss it..... it's too near reality for him..... you've got enough to face, without actually facing your mortality, cos he faces it every day, every ache and pain that he's got...it's the cancer.....he's got enough on his plate without erm .....and (his wife) she can't come to term with it and, er, he says he can't talk to her about it.."*

*Margaret, age 64*

Some participants commented that people might never be aware of being terminally ill and therefore never feel the need to discuss end of life wishes. This might sometimes be best for individuals, if not for their family. In the quote below, a participant tells the story of a friend's mother, who was diagnosed with pancreatic cancer:

*...”.... they said, well, they could put a stent in.....but it wouldn't last forever..... she just went away perfectly happily thinking ....”they'll do something else to fix it ....But of course, four years later she died...went into hospital....after the stent had finished its useful job...died the next day. And the daughter said, “..when we went to clear her flat....there were all these notes about...the things that she had to do when she came home” .... she hadn't thought about death, she...was just getting on with life.....”*

*Mary, age 70*

In summary, although the best time to discuss end of life wishes varies between individuals, there is a general view that, for most people, the best to talk about these things while well.

#### **8.2.3.6 Types of conversations about end of life wishes**

A number of participants commented that discussions about end of life wishes need not be lengthy or frequent, it might be something that is done only once, or only when something changes. These discussions could be easy and positive, provided they were approached sensitively and when the time was right. The most difficult part was starting a conversation; conversations therefore often followed a 'prompt' which either occurred naturally or was used purposefully as a conversation starter. In the quote below, a participant describes how she started conversations which would enable her to find out the funeral wishes of various people close to her.

*...”....I didn't go barging in and say “Right I want to know what you're going to do when you're dead”, you know there are things, there are opportunities and little times that pop up, and....you just sort of say, “Well what would you have?”*

*Margaret, age 64*

Some participants suggested that talking to one person on one occasion was not sufficient, that it was important to write things down and perhaps to discuss things

more than once or talk to more than one person. This would enable people to be more certain about what was wanted and to more easily share and agree this with others. The quote below illustrates the latter point.

*...."if you've had a conversation with one person and you haven't had it with another, erm, then if it's written down, the person who's had that conversation can say, "look it's been written down, this is what they said, here's the evidence..." "*

*Julie, age 40+*

#### **8.2.3.7 Barriers to talking about own end of life wishes**

Many participants reported that they were able to talk freely and openly about their own end of life plans and preferences, and also reported that many of the people around them were willing and able to listen and join those conversations where appropriate. This is illustrated in the quote below:

*..."I know what both my neighbours want, I know what my best friend wants, and through this conversation, you know, and I didn't know that my son wanted to be buried, I just took it for granted that because I wanted to be cremated that he did, "No you're not cremating me mother" and then because I'd had the conversation with him, I know what his wife wants...."*

*Margaret, age 64*

However, most participants identified factors they perceived as preventing discussion of end of life wishes, either from own point of view or from observations and interactions with other people. These perceived barriers are described below.

#### **Not a priority**

Planning for end of life might not seem a priority when death seems a long way away. This applied both to both younger participants and to some older participants who were still active and well. The quote below is from a 75 year old participant.

*...."... when it comes to my funeral, I probably would say to the family, "I want this hymn, that hymn and that hymn". I'd probably tell em that.....but at the moment that seems so far off that death doesn't, it doesn't seem relevant at the moment..."*

*Joan, age 75*

Some participants suggested some individuals may not be 'planners' in general, and planning for end of life is no different, with some people finding it easier to wait until 'the time comes' before making plans.

Some people might have no interest at all in planning; which may continue even close to death, as this quote illustrates.

*.... "....my mother-in-law is 87, thinks it's weird, to actually plan for anything, cos she won't be here anyway, so it doesn't matter"*

*Andrew, age 50+*

### **Fear of death**

It was a common perception that talking about end of life wishes was more difficult if people had difficulty facing their own death, or that of those closest to them, due to extreme fear or sadness. This fear could have an influence at any age or at any stage of life.

Almost all of the participants described a sort of superstition that they had seen in others, that talking about end of life plans, or making a will, might bring death closer. Some suggested that this might be particularly true when people were ill. It could even occasionally lead to people with a terminal illness refusing to accept care from professionals. The quote below illustrates this superstition.

*.."...I think it becomes a fearful thing that if you, perhaps if you discuss it, it brings it more into reality.....it's almost a superstition isn't it? "Don't let's talk about it, and, and it won't happen..."*

*Janet, age 58*

Some participants talked of friends or relatives with an extreme fear of death, who generally avoided talking about death because of it. This extreme fear was perceived to affect only a small proportion of individuals. In the quote below, one participant describes the attitude of her 77 year old aunt.

*....."..... she is terrified of death, terrified. If she sees, erm, a funeral car in town... ....she'd have to turn and go the other way. You daren't talk to her about death, at all, ....it's not something I could discuss.....she'd probably throw something at me"*

*Jane, age 40+*

A milder fear of death, often described as a fear of the unknown, was believed to be very common. Participants believed it to be both a cause of and a result of people not talking about death. The quote below illustrates this point.

*“...some people don’t like talking about death....it’s an unknown and those things that are unknown are frightening.....and if you don’t talk about these things, they do become unknown.....they become, er, mysterious and frightening..”*

*David, age 60+*

One of the most common fears was the existential fear of what was ‘on the other side’. Religious faith could play a role in this, often in a positive way, but not always. Some suggested the importance of being certain in belief, whatever it was, as a way of ‘making sense’ of death. Participants’ suggestions for reducing existential fear included exploring beliefs about life and death, and discussions with other people, as summarized in the quote below.

*...”...you’ve got to read, you’ve got to talk, you’ve got to share, you’ve got to explore...”*

*Ann, age 65*

The fearful unknown could also encompass more practical aspects of death or the physical process of dying. Some participants also viewed some of these aspects as mysterious or hidden. People might also fear that they would not cope well emotionally with illness and dying. Others almost fear living too long, and developing dementia or otherwise becoming dependent. The quote below illustrates this theme.

*... “.....what life’s like in a hospice.... It’s all cloak and dagger.....it’s all something you couldn’t know about....funeral parlours and crematoriums, we none of us really know what goes on, it’s all secrecy”*

*Christine, age 65*

Participants suggested that fear of the unknown might be reduced if people knew more about what dying, and diseases of old age such as dementia, actually looked and felt like, and of the organisations and rituals that surround death. They also commented that many fears may be unfounded; four participants talked about a time in the past when they had been very close to death, and all commented that it

was not distressing in any way. In the quote below, a participant describes his experience of being close to death.

*...”I know I wouldn’t mind dying, if I had to die tomorrow.....because it’s, it’s just like going to sleep.....in fact when you get to that state, you’re not bothered at all really...”*

*Robert, age 69*

On a slightly different theme, there was a perception that some people who have been diagnosed with a life-limiting illness feel so sad about losing their life that they have difficulty accepting it, and therefore do not want to talk about it. The quote below describes this as ‘not wanting to let go’.

*.....”Accepting that you’re dying is quite a hard thing to do, just to let go of what’s precious to you, you know, your family and your, your life...”*

*Ann, age 65*

### **Not wanting to upset friends and family**

This theme relates to a fear of upsetting family or friends when talking about end of life wishes, or of a wish to protect them. Parents often wished to protect the feelings of adult children; others wanted to protect spouses or partners, some considered both. Occasionally, having conversations about end of life wishes really did upset somebody and it was necessary to end the conversation. The quote below describes such an event.

*....”my wife got very upset, I mean she was crying ..... we have talked about it, we talked about our wishes in relation to cremation or burial, erm, and that was alright, but talking to a third party (their son) made it somehow more er, I don’t know, it certainly got to her... Erm, so, er, you know, I sort of, left the topic at that stage ....”*

*George, age 85*

Some participants suggested that this fear might often be unfounded. Others suggested that the consequences of not talking could be worse than any discomfort caused by any discussion. However, a solution which would not involve upsetting anybody was suggested. Instead of discussing their wishes, a person could write

them down, and make sure the other(s) knew where the written information was kept, to use in the event of their death. The quote below describes the advice that one participant gave her friend, who had a terminal diagnosis and whose wife did not want to discuss it.

*...” he can’t talk to her about it.....I said “well listen” I said “you’re not doing her any favours” I said “write it down, write it down put it in an envelope”....*

*Margaret, age 64*

### **Resistance from other people**

Sometimes a person might wish to talk about their own end of life wishes, and find that the people close to them do not want to listen and close off the conversation. The person who wanted to talk often did not fully understand the reasons for this.

Participants described successfully employing three different solutions to this problem. The first was to be persistent and almost forceful. Some participants, as illustrated in the quote below, had done this with adult children. The second was to introduce the idea a little bit at a time, more often used with spouses or partners. The third, as previously described, was to write the information down, and let the person know where to find it.

*.....”.....it’s took me ages to tell them, cos every time they keep saying, “No, no, no, don’t talk about it mum”, “Yes you do, yes I do, and you might not want to talk about it, but I want you to know”, and it’s been a few crossed wires.*

*Jacqueline, age 55*

### **Isolation**

Some participants knew of people who might not have anybody to talk to about their end of life wishes because they had become isolated through living alone, illness and poverty. Some also suggested that this situation is becoming more common, as social care is being cut back and providing voluntary services is becoming more difficult and expensive. The quote describes the situation from the view of participant who was involved in voluntary work with older people.



*....."many of them become isolated.....so they don't have the opportunity to talk to anybody... one of the things in the church that we struggle to do is.....getting the less ambulant together.....your insurance won't cover it.....protection issues as well..... and as local authorities are withdrawing, erm, their care...and various other things, people are becoming more and more isolated... .."*

*Andrew, age 50+*

#### **8.2.4 Talking with others about their end of life wishes**

Many participants had talked or wanted to talk to family members about what a person planned or wanted, so they could be prepared in the event that that they became ill or died. Some wanted these conversations with all adult family members; others only with family members who were ill, frail, or elderly.

Participants who had had these conversations while a person was well often told of how glad they were, especially if the person died suddenly or developed dementia. If they found that what a person wished for was not what they would have assumed, this gave them an added sense that the conversation was worthwhile, even if difficult. This is illustrated in the quote below.

*..."I managed to find out what I needed to really. Cos, you know, especially like from my upbringing.....cremation would never come into it, I'd never even thought about it. I would have just had him buried..."*

*Jane, 40+*

Participants who cared for family members in their final illness found it particularly important to find out the family member's end of life wishes, as this would enable them to 'do the best they could' for them. This theme could also relate to arranging a fitting funeral, whatever the circumstances of death. The quote below describes this in relation to the participant's mother, who she had cared for at home.

*..."what helps is just to know....that you are doing the best you possibly can for that individual.....my mum ...didn't want to go into hospital...that was the one thing she was adamant about..... it got to a point where the doctor actually said ...she should really be going into hospital, I said, "No", I said, "My mum doesn't want that", .... I just knew what she would absolutely hate"*

*Julie, age 40+*

Participants also had mutual conversations with spouses and partners about what each of them would want, and about the content of their wills. This generally seemed to be easier than talking to other family members, although some partners did not want to engage in the conversation, which could be frustrating.

The immediate motivation (or excuse) for conversations about another person's wishes often originated from an external 'prompt', as for example in the first quote below. Although participants sometimes worried about starting conversations about another's wishes, and how the other person would react, these conversations could often be very natural and positive, and had the potential to help bring people closer. In the second quote below, a participant describes conversations she had with her daughter.

*... "... there was a programme on TV about, em, er organ donation, and I said to her "Look, if worse came to the worse, what would you want me to do?"....."*

*Julie, age 40+*

*.....".....I just talk to her like I'm talking with you, and it's not difficult.....and , we just chat about it as if it's, and now I know everything about her, if anything was to happen to her, her or (daughter's husband), for the future of the children..".*

*Jane, 40+*

These conversations could also occasionally be difficult, emotional or uncomfortable, especially if somebody was already in their final illness. Some participants thought that, however difficult it was to talk, it should be done anyway, because the consequences of not having the conversations could be much worse than any discomfort in having them, as exemplified in the quote below

*... "...with some people, you know, those conversations might be difficult, but compared to how difficult it is to then to try to carry out wishes for people, or, or, know where to start, because unless people say....."*

*Christopher, age 30*

Others suggested that some people 'don't want to go there', whether they are well or aware of a life-limiting illness, and that this should be respected, as seen in the quote below.

*...” I think some people if they don’t want to go there, then obviously they’re not ready. They go there when they’re ready for it, and maybe some of them are never ready...”..*

*Karen, age 50*

#### **8.2.4.1 Barriers to talking about another person’s plans or preferences**

##### **Fear or sadness associate with the thought of losing somebody**

Many participants feared or worried about losing people close to them through death, or felt so sad at the thought of losing somebody that it inhibited them from talking about what might happen when they die. People of all ages expressed fears that they would not cope well emotionally with the death of somebody close to them. The types of fears varied by age and individually between participants, but most often related to losing parents. This is described in the quote below.

*.....”.....the daughter, she still pooh poohs it a bit.....she can’t quite get her head around the fact that her mum’s going to go one day I suppose... she’ll talk about (husband) because he’s her stepfather .....my stepdaughter.....she’ll talk to me no problem, so I think it’s the closeness must be a problem, and when I look back, I think at first when I realised my mum was getting old I found it quite difficult..”*

*Patricia, age 74*

One participant said he felt so sad about potentially losing a spouse or partner that it affected his ability to discuss their end of life preferences together. He suggested it may be easier to talk with somebody close if there was some sort of practical guide to use, which might help with focus and distance the conversation from the emotional. He explains this in the quote below.

*.....”.....it’s a heart-ripping thought.....to try and have it as a very practical discussion.....feels sort of disrespectful to the idea of us parting.....To just have a very practical guide.....that you can then, goes deep into whatever you need to go into, between yourselves.....so I’m not totally lost in deep waters...”..*

*Peter, age 50+*

Others worried about how they would cope alone if they lost their partner, or how they might cope with the necessary arrangements immediately after a death. People who were vulnerable in some way might be particularly prone to this worry. This is illustrated in the quote below, where a participant talks about his wife, who had mild dementia, and who became upset when he talked with her about his will and funeral wishes.

*....."I don't know how many people are prepared to deal with the routine chore of registering the death, erm, getting death certificates and notifying all sorts of people; the pensions people and .....you know, all those sorts of practical things... my wife would be, erm, troubled, and think, "I can't do all those things, I can't do it".."*

*George, age 85*

Some participants talked of how the fears that some people have regarding bereavement are generally unfounded, implying that there might be a potential to reduce these fears. One participant spoke of how, after the death of her mother in hospital, she had been guided through the process of registering the death and arranging the funeral. She also described how she had already taken over roles that her husband used to perform before he developed dementia, and how easily she was able to cope with these new roles.

*....."I have friends who still have husbands and they're saying, 'Oh I don't know what we would do if they die, because I don't know how to work a computer, I don't know how to do the bills', but you do do that, I mean my husband used to do all of that....and then I had to take over ....so.....they would cope, because you do..."*

*Joan, age 75*

### **Lack of confidence or experience in talking about end of life wishes**

Many participants described a lack of confidence, which could lead to anxiety, in talking about another person's end of life wishes, especially if the person seemed reluctant to discuss it. This was often expressed as 'not knowing where to start', and was often related to lack of experience, or lack of positive experience. Once a conversation had started, many people found it quite natural.

Some participants suggested people might benefit from some ideas on how to start these conversations. One participant went on CLWDW 'How To' workshop, which she said gave her the confidence to talk to both her mother and her daughter about their wishes. In the quote below, she describes this process.

*..." straight away, once I'd done my training.....I said, ".....I could pass away before you Mum, but I need to know, what am I to do with you?".....that course really, and it's, it done me good.....how to open conversations.....because you just, a few years back.....it was just like, 'Oh this is wrong, I can't say it, oh no this is not right'..."*

*Jane, age 40+*

Participants who lacked confidence or experience in talking about end of life wishes also often worried that the person they were asking would not react well, or that the conversation would be awkward. More often than not, if these fears were overcome and the conversation took place, they found the experience to be positive.

Most participants had successfully discussed another person's end of life wishes, and shared their advice on the most effective ways to start a conversation. A common technique was to talk about their own end of life wishes first, even where the other person had a terminal illness and they were well. In addition, external events might be used as 'prompts'. After having a successful conversation with one person, it was then often easier to have similar conversations with other people, as confidence had increased. In the quote below, a participant who was caring for a partner with terminal cancer describes how she discovered his funeral wishes.

*...."....I said, "Phil...I need to know.....I could die before you....but I want you to know what I'd want if I was to die", and that was how I had to start a conversation with him.....Fortunately enough, I managed to find out that he wanted to be cremated.....but other than that.....he died too sudden..."*

*Jane, age 40+*

### **Resistance of the other person**

Sometimes an individual would feel confident asking about end of life wishes but others would not wish to continue the discussions. Some eventually had success using the techniques described previously, while others used a combination of persistence and asking only for the pieces of information they thought most

important. The quote illustrates how sometimes it was only possible to find out the most basic wishes.

*...”... it was only in the last week of her life that I helped her fill just one very specific part of (advance care planning document)...that she didn’t want to go into hospital, she wanted to die at home. Erm, the rest of it, we made up as we went along, because...she ...wouldn’t talk about what she wanted..”.*

*Julie, age 40+*

However, as described earlier, most participants accepted that some people just didn’t wish to talk about end of life wishes and this should be respected.

## **8.2.5 Specific end of life issues**

### **8.2.5.1 Wills and inheritance**

#### **Importance and function**

For most participants, the most important preparation for death was to make an appropriate will. The majority had made a will, and those who had not made a will all expressed their intention to make one. Wills were sometimes considered separately from other preparations for death, as part of the financial administration necessary to look after the family throughout life, as a way of making sure money goes to family and unnecessary bills such as solicitors fees and inheritance tax are avoided. As such, making a will was considered a responsibility. This attitude is illustrated in the quote below.

*...”...making a will is not so much....for the benefit of me.....I want to look after the family .....you make a will, otherwise it goes to probate, and the government .....take money....”*

*Robert, age 69*

Wills were considered important for people of any age, in case of unexpected death. This was even more important for people with dependents, and with advancing age or in the case of life-threatening or life-limiting illness. The quote below describes how one participant tried to persuade her young adult son and daughter to make wills.

*..... "I says 'have you got any wills?', 'Mum, we're only 25', I says 'You're only 25, but you could be dead tomorrow, you work in a service station, you go up and down the M6 regularly, you know how the M6 is from here to Stafford, you know'...."*

*Jacqueline, age 55*

Some participants talked of the importance of the personal aspects of a will, ensuring that objects of sentimental value were given to the right people. It also sometimes included a wish to leave an emotional legacy in the form of a personal message or some knowledge of family history. This is close to the concept of an 'emotional will' which was a topic discussed at LDWD public health events. This desire to leave some written memories is illustrated in the quote below.

*..... "I'm putting things on the computer..... how, sort of when I was four and five and my mother and father and so I, and so I'm just making notes so that when I'm dead, the family will have something to go on because er, our daughter likes old photographs of my grandmother and that sort of thing..."*

*Joan, age 75*

Often participants had experience of situations where people had died without a legal will, or without updating a will, and this had caused problems after their death. It was commonly described that people had not made a will because they either died suddenly or had become ill and 'run out of time' before they could make a will. This scenario is described in the quote below.

*..... "..... sadly on my wife's side who lost her mum at a young age to cancer.....I've seen how messy that can become because people haven't put into place a will.....I've seen how people..... that haven't had their kind of last will and testament carried out because of they've run out of time..."*

*James, age 30*

Some participants talked of how a will was particularly necessary in some 'complicated' situations such as after divorce and re-marriage, or where couples remain unmarried. In some cases a more complex form of will might be appropriate. Where dependent children or vulnerable adults are involved, it might be important to have other documentation, such as power of attorney or trust accounts.

Preparing a valid will was considered more important than talking about it. However, it was considered important to agree the content of the will with partners or spouses, and to let family know where to find the will and other important items. Not being able to find a will could have the same consequences as there not being a will, as the quote below illustrates.

*...”....He couldn’t find a will. He’d been told there was one, but they were a very feuding family....and there was property involved...and then you’ve got the probate ....and in the end they got a solicitor to sort it out ....that cost a lot of money...”*

*John, age 72*

### **Barriers specific to making and discussing a will**

The main barriers specific to making and discussing wills were lack of knowledge about wills and lack of money, which could often, but not always, go together.

Participants perceived that lack of financial or legal knowledge could leave a person unaware of the benefits of making a will, and consequently not motivated to make one. Some might lack awareness of the value of their own assets, others of inheritance laws. Alternatively, people might believe that the process of making a will is too complicated, or that wills are too difficult to change at a later date. These issues are illustrated in the quotes below.

*.....”I think to, to be quite honest, wills are sort of something people don’t want to talk about...they can be quite complex, and I think, I think that’s...what puts people off...”*

*Tony, age 69*

People might sometimes be unable or unwilling to pay for advice about making a will, or may feel that they have nothing to leave anyway.

*....”... I can’t get that information very easily, and I keep feeling like I’m being guided to solicitors that are going to rip me off, you know...”*

*Peter, age 50+*

Participants therefore often felt there was a need for information about wills which could be accessed free of charge. Two participants commented that some charities



run wills workshops or a free will-writing service, which could be useful, as the advice provided was believed to be sound. In the quote below, one of the participants describes this process.

*.....“I know....one or two other, erm, organisations will actually pay for you to do a will, as long as you, well they don’t specifically say that you have to leave something to us, but they will encourage you to make a will and pay for it in the hope that you’ll leave something to them”*

*Tony, age 69*

Not feeling comfortable talking about inheriting money, for fear of appearing to want the money for oneself, could sometimes be a barrier to other people asking about a will. The quote below illustrates this.

*...“there might be money somewhere, there might be bank accounts, but it is a difficult thing..... when someone passes or, you know, it’s that awkward thing of, well.....is there an estate? And you come across as kind of gold digger or something ...”*

*Christopher, age 30*

#### **8.2.5.2 Funeral wishes**

##### **Importance and function**

Letting people know funeral wishes was considered important to many participants, although generally not as important as having an appropriate will. Many younger and middle aged participants had told their family members whether they wanted to be cremated or buried. Some older participants had also planned and paid for their own funeral.

As with wills, talking about funeral wishes was considered mainly as a benefit of those left behind, sometimes thought of as a ‘gift’ to the people who will arrange the funeral, as described in the quote below.

*.....”...by telling and talking it’s giving your family and friends a gift, because it’s taking away all the stress when you are so vulnerable and everything is happening to you, the last thing you want to do is worry are you doing the right thing...”*

*Margaret, age 64*

The majority of participants did not express particularly strong feelings about their funeral wishes, other than whether they wanted to be cremated or buried, or whether they wanted a religious service; others expressed quite detailed ideas of what they wanted for their funeral, although these generally seemed to be formulated with other people in mind rather than themselves. This is illustrated in the quote below.

*...”...I want to be cremated in a cardboard box..... I want a church service because my faith is very meaningful to me...(then)...just wave me off goodbye and go and have a party or whatever you do..... well I have said this to them too, if you think this is a load of rubbish, you do what you want, because I won’t be there and it won’t make any difference to me at all”*

*Mary, age 70*

Younger participants generally expressed a greater motivation to discover another person’s funeral wishes (often a parent’s) than to let their own be known. Arranging a funeral was often considered to be that last thing that a person did for another, and it was important to get that right.

Participants who knew the funeral wishes of relatives who had died described how beneficial it was to them in terms of reducing stress in the immediate aftermath of bereavement, giving people the satisfaction of knowing they had done their best for the deceased, reducing feelings of obligation and reducing the possibility of family conflict. The quote below illustrates these benefits.

*....”my husband died just suddenly, but we’d always talked....we’ve walked on the common and we always said, er, ‘you can bury me here’ and he said, yes’, he said, ‘put me here’...we knew what hymns we wanted, so when he did die, his funeral was the least of my problems because I knew everything that was going to happen, it was so easy..”*

*Margaret, age 64*

Funerals were considered important to the grieving process and several participants observed that funerals planned by the deceased can be particularly personal and hence healing for people attending. Several participants described very individual, personal funerals that they had attended. The quote below describes one of these funerals.

*...”..she had a black coffin and everybody had a silver pen to go and write a message on it....and she was cremated with all those memories and messages.....good funeral that was..”*

*Laura, age 32*

Where a person did die without letting people know their funeral wishes, there were still ways that it could be made easier. Families could talk together and with friends to decide what seem ‘right’ for the deceased person, and funeral directors and clergy could be very helpful in talking this through. The quote below illustrates this experience.

*...”.....some of the funeral directors can be quite helpful.....talk to the family of, what would be their interest? What did they like? What, you know, try to get a picture of them and try to plan the funeral around the person...”*

*Ann, age 65*

### **Barriers specific to talking about funeral wishes**

Barriers to planning for and talking about funerals were similar to those for wills, but were of a lower magnitude, because people are able to delegate most of the work to their relatives, whilst still letting them know vaguely what they wanted, e.g. to be cremated or buried. However, some people may be reluctant to talk about their funeral if they feel they are unaware of the options available, or about how much they cost; or if they are unsure whether they will be able to leave enough money to pay for the funeral. The quote below illustrates the problem faced by people who do not have sufficient assets to pay for a funeral.

*...”..My mum’s not rich.....where’s the money going to come from to pay for her funeral? ....she’s penniless.....so, what happens there? Does that mean I have to pay? I don’t know ..... if I was to try and talk to my mum about her funeral, there is an immediate block of “Who’s going to pay for this?”, that’s a massive financial threat to her, that..... “I can’t pay for my own funeral.....is it a burden on....my family?”...”*

*Peter, age 50+*

### **8.2.5.3 Treatment, care and capacity at end of life**

#### **Importance and function**

End of life care preferences had four main themes, which overlapped slightly. The first was medical treatment in a life-threatening situation, e.g. stroke or head injury, where capacity to make decisions had been lost. The second was care at the very end of life, when unable to express own wishes, e.g. preferred place of care or preferred place of death. The third was medium to long term care, e.g. in case severe dementia or another long-term condition which interfered with capacity to communicate and make decisions. Some of the younger participants also talked about organ donation.

The majority of participants did not mention talking about or recording their own wishes for any of the three main aspects of end of life care. The most commonly mentioned discussions were about what they would like in the event of a sudden illness or injury leaving them potentially brain-damaged. The quote below gives an example of this. Only three participants mentioned discussions about care at the end of life; two of whom had been diagnosed with cancer, one in the past and one currently. One mentioned a conversation she had had with her parents about their possible medium to long-term care.

*"...I know, turn the plug off, there's no brain activity or it looks like (husband's) going to be a vegetable, the plug comes out..... (he's) been told he can't unplug me and he can't get remarried.."*

*Sarah, age 37*

Many talked theoretically of what they thought they would want in the case of terminal illness and poor quality of life, suggesting that people often do think about these issues, but intend to confront them only if and when they arise.

Several participants commented on the potential benefits of talking about end of life care wishes when still well, as a way of becoming familiar and hence comfortable with these conversations before death seems close, and as a way of educating oneself about the options available or getting used to those types of discussions before they were needed in reality. One participant likened it to having a birthing plan when pregnant; it was something which was good to have, even though it could be changed at any time. The quote below illustrates the perceived emotional reasons to have these discussions while well.

*...”....I don’t know what it would be like if we actually did have a serious diagnosis hanging over ourselves..... but I think actually having the discussion and the joviality of it, is the best time to, because when there’s a serious aspect to it, I can see families just don’t know how to deal with that, that emotion of the reality..... make it jovial, make it light.... somewhere to move on from, so that when it does become serious ..... you’re not left shocked at the nitty gritty bit...”*

*Sarah, age 37*

Two participants suggested that, as it was not possible to foresee every circumstance, it was important to explain a certain course of action, and to write that down. When discussing possible long-term care wishes, it was also considered important that the conversation was two way, as the wishes of both the people would need to be taken into account. This is described in the quote below.

*...”...I’ve also said to my parents, you know, ‘If you’re ill, then I’ll move you in with me’ at which point they’ve been horrified, and said, ‘No, we’ve got money in place that we will have carers or we will go into a home..’..*

*Sarah, age 37*

Talking about end of life care wishes was more important and relevant to people who had been diagnosed with a life-threatening illness or were aware of being close to the end of their life. The main motivation was to receive the care wished for, which could include a wish to make their care as easy as possible for others. One participant, who was a volunteer in a hospice and had in the past been diagnosed with cancer himself, had a clear and detailed view of what his end of life care would look like, and had let his family and friends know this. This is shown in the quote below.

*.....”... I have a, a severe objection to being trapped in a bed in a hospital, with, er, I don’t know, Jeremy Clarkson, or somebody on the television, shouting at me..... I want to be as far as possible out in the open air.... I want my family around me, I want to be dressed, I want my mouth to be clean, I want to, I want to have nice music, erm, and I want to be comfortable. I don’t want any pain...”*

*David, age 60+*

Once a person became ill, letting family members know about end of life care wishes could reduce the risk of family conflicts over a person's care, which might interfere with caring for them. This view is illustrated in the quote below. One participant, who worked as a physiotherapist for Macmillan Cancer Care, commented that it might also be important for the family to talk between themselves, as they may not be able to fulfil the dying person's wishes.

*....."...in families, when somebody's dying, it's not just the person who's dying it affects, em, all the old stuff that hasn't been resolved in the family comes up...so if a person who is dying hasn't expressed their wishes, it's almost like a bun fight...and if you're not careful, the person who's dying actually gets forgotten about".....*

*Julie, age 40+*

Discussions about end of life care also frequently involved, and were initiated by, health or social care professionals. Professions specialising in caring for people who were dying were considered well placed and able to help people with these plans. People working in hospitals, especially doctors, were generally believed to have more difficulty with this role, which in some ways conflicted with their usual roles. The quote below summarizes these views.

*...." ....the district nurses .....they had fantastic conversations with my mother-in-law, the Macmillan nurse who looked after her was fantastic as well..... they were open, honest, gentle ..... (but)...when you are in hospital and it's an environment where you are there to save people.....letting go and doing whatever is right for that individual as part of the process of letting go, and I think, still, a lot of medical professionals have a difficulty switching....."*

*Julie, age 40+*

One participant, who worked with people who are dying of cancer, thought that, in recent years, patients and families were becoming better able to talk about end of life care, partly due to recently improved skills of medical and healthcare staff.

### **Barriers specific to discussing end of life treatment and care wishes**

The main reason that most participants had not engaged in advance care planning or discussed their end of life care wishes seemed to be that it was not a priority to

them. However, some participants also mentioned other factors, which might make people question whether planning is worthwhile.

Some commented that they might think they would know what they would want within different scenarios, but might change their mind in the event. By way of example, one described her grandfather's preparations and actual reaction to a terminal illness, summarized in the quote below:

*....”...my father was a hospital pharmacist.....before he retired  
.....(he) brought with him some tablets.....he knew that if (he took) the  
tablets...that would be the end for him.....I think he was afraid of long-  
term illness and disability ....but.....he died of....T-cell lymphoma ..... and  
he died naturally, he didn't take the tablets.....and we found them when we  
went to clear his house.....”*

*Jane, age 40+*

Others recognized that, for various reasons, a person's advance wishes could not always be met. This is illustrated in the first quote below, describing a participant's conversation with a friend whose father was dying in hospital, although he had expressed a wish to die at home. Where people have no family or close friends to care for them, they may also have fewer choices in old age, and therefore advance care planning may seem less worthwhile. Alternatively, families may be unable or unwilling to care for a person as they would wish, as described earlier. Others were unsure whether their wishes would be respected by health services, as illustrated in the quote below.

*...”....I like this business of, erm, you know, your wishes, you know, for your  
end of life care, or.....if you were to end up with, you know, dementia or  
anything like that.....I mean it's nice to be able to plan.....whether it'd  
actually be adhered to is another matter, isn't it?*

*Jane, age 40+*

One participant commented that 'preferred priority of care' forms used by health services could be a useful tool for thinking through and recording end of life wishes in a way that might be accessible and respected by health service providers.

### 8.2.6 General conversations about death

General conversations are defined here as the sharing of thoughts, ideas, and information about death, dying and bereavement. People might have these conversations along with more specific conversations about their end of life wishes, but might also conduct them separately and with a wider range of people.

Some participants, particularly older participants, had talked with family, friends, and acquaintances about other people's deaths and the fact that they will die themselves. Younger participants did this less, but talked of older family members making passing comments, such as "Well I won't be around then". Conversations between friends and acquaintances often used humour, as described in this quote below.

*....."we'd been to Ikea to buy some wardrobes and.....we'd had them in tucks because they were trying to.... sell us these wooden interiors for this wardrobe and we said "well, you know...what age we were, we'd not be looking for something with a ten year guarantee..."..."*

*Patricia, age 74*

These conversations seemed to play a role in helping people to emotionally prepare for death and share information about things that they might need to consider, as well as friends bonding over common thoughts and experiences. The specific benefits identified by the research participants are described in more detail below.

#### 8.2.6.1 Focussing on what is important in life

Several participants talked of how thinking about and talking about death increased their consciousness that life is finite, and that this helped them to live life to the full. Conscious awareness of the limits of their own life-span, and the fact that life could end sooner than expected, helped some people to focus on what they wanted to do with their lives, and how to get the best out of life. This is illustrated in the quote below. Sometimes this focus came in the form of a 'bucket list' of things to do before they die. However, occasionally this reflection could be difficult, for example, if a person felt they had not achieved all they wanted in life.

*....."I think talking about death actually enables you to, to consider life and consider where you're at.....I think just looking at the fact that there is an end.....it's a mirror to reflect on, what are you going to do in life. So, "Am I*



*happy in this relationship?”, “Is this the job I want”, you know, “Am I good to the people around me?”*

*Christopher, age 30*

#### **8.2.6.2 Preparation for death**

Conversations with friends could be helpful as way of preparing emotionally for the eventuality of death, and as a way of exchanging practical information about death and preparations for death. They could also provide including ‘prompts’ to thinking about planning and discussing end of life wishes. Often these conversations included humour, as illustrated in the quote below.

*...”..conversations used to be about, um, children and schools and things, now the conversation turns to erm, funerals, and erm, wills and stuff ...everyone was joking about....somebody said, “Well actually we won’t need any funeral directors....in our group...there are two ordained people.....they can be the priest, and so and so’s good at sewing, she can sew the shroud..... it was, in a way I suppose rehearsing.....it’s not an issue they are facing now, but it is an issue that they recognise is on the horizon for them..”*

*Mary, age 70*

#### **8.2.6.3 Contribution to the development of a ‘compassionate community’**

A common view was that, if people talked more about death as just an ordinary topic of conversation, they would find it easier to talk to and support people who were dying, caring for somebody who was dying, or bereaved. This would be partly due to having more experience of talking about illness and death, and partly due to greater awareness of what people need. The quote below summarizes this view.

*...”...we don’t talk about it enough, they don’t know what to say, and they are frightened of saying the wrong thing...and that because the conversation isn’t normal, isn’t ordinary. And if it became ordinary and natural then people would actually know how to talk about that..”*

*David, age 60+*

## **8.2.7 Support for people who are dying or bereaved and their carers**

### ***8.2.7.1 Social experience and needs of people who are dying and their families***

The situation and period of time that participants referred to as 'dying' varied widely, depending on their outlook and the trajectory of decline of the person they were describing. It could refer to the final few days or hours of life; or to becoming very ill with a terminal illness; being diagnosed with a terminal illness; having a number of life-threatening conditions; having a life-limiting illness such as dementia; or simply 'getting old'.

Participants reported that, when they were aware that a family member, or anybody that they knew, was close to death, it was important to them that the person who was dying was as physically comfortable and pain-free as possible, and also that they were 'at peace' or ready to die. The quote below describes a participant's reaction to somebody close to him who was close to death.

*..."......I wanted her to know, I wanted to tell her how much we loved her and everything, but I wanted her to be at peace, and that was a really important thing.....you want everyone who's passing to be at peace....."*

*James, age 30*

Participants also perceived that people who were dying would wish to know that their life had been worthwhile, and that their family members were 'at peace' and ready. In the first quote below, one participant who had recently been close to death confirms that perception as she remembers a conversation she had had with her daughters at the time. However, when death was close, sometimes very strong emotions prevented people from talking about these things, even when they wanted to.

*..."....I was able to say to them..."...I've had a good life.....I feel good, so, you must feel good too.....I think it has been good for her, to know that I was not distressed in any way at all"*

*Mary, age 70*

In the quote below, a participant describes wanting to talk to his grandfather on his last day, but being unable to say what he wanted to say.

*....."I'm sure he knew, but I just wanted him to know certain, a few things.....and I was crippled, I just couldn't say it, and it was like, and I did speak to my mum about that actually, and she said "I was the same"..."*

*Chris, age 30*

Because of the need to see that a person was at peace, it was often important to be with them when they died, and sometimes to have some support from others to do that. In the quote below, a participant describes how he supported an elderly woman whose sister was dying.

*"...her sister was quite ill....in hospital...we took her across and she said, "Now read something from the bible".... so I just read a few passages. Whilst I was reading she died.....and so her sister, although she was upset, was pleased, because she said she had a smile on her face..."*

*Michael, 60s*

Family members often willingly undertook practical caring duties for family members, and generally wanted to 'do their best' for the person, as described previously. However, they could sometimes grow to resent the person they are caring for, especially if they had to cope alone. Carers of a person with a life-limiting illness needed to continue with their own social lives and take regular breaks from caring. Friends and other family members could assist with that, although some chose to use paid carers for respite. Health care professionals were valued for helping with practical tasks.

The person who was being cared for could themselves be a source of support or stress for their carer. In the quote below, one participant describes the difficulties she encountered because her partner would not talk with her about the fact he was dying.

*...".. He wouldn't have Macmillan nurses in, so I had no support off them..... I was like, "Oh my god, I need some support, I really, I don't know where to turn"..... My (family)....they're not there with any knowledge of 'what's going to happen?' 'where do we go?', you know..."*

*Jane, age 40+*

One participant described being unable to acknowledge to her friend that he (her friend) was dying; but this did not stop her from otherwise being supportive, including being there with him when he died. This suggests that it is possible to be with and support somebody who is dying, while not acknowledging the fact. The quote below describes that situation. Other participants described how people could support their friends in a range of ways, which sometimes included talking about the illness and death, but could also include practical support such as taking them out, attending medical appointments or simply remaining friends and 'being normal'.

*"..... He knew he was dying and then he died..... I would always look on the bright side.....I'd probably say, "Well never mind, there's always hope".....I would be there to make them coffee and sympathise....but, talking about it.....I would try to put the best face on it because I wouldn't know otherwise how to handle it..."*

*Joan, age 75*

When people were ill, maintaining contact with friends was often more important than talking about their illness. They might not need or want to talk with all of their friends about dying. In the quote below, a participant recounts something that her friend, who was dying from cancer at the age of 28, told her.

*....."when my friend..... was, was coming to the end, she said, "You know what...people are just coming up to me and saying, 'shall we go and have a coffee'", she said, "that, that was great" and..... nine times out of ten she didn't even talk about how she was feeling or about the illness..".....*

*Laura, age 32*

Some people found that friends and other people in their social network avoided them once they were diagnosed with a major illness, whether or not it was known to be terminal. They generally attributed this to the other person not knowing what to say, but still found it upsetting, as recounted in the first quote below by a participant who worked in a hospice. In the case of people with long term condition such as dementia, they might find that, as the disease progresses, people stop visiting, because they are no longer 'themselves' and people don't know how to talk to them.

*...."..I hear sometimes from patients, erm, who have maybe been diagnosed with a life-threatening illness, one of them said 'you find out who your friends are'...Cos he said 'some will stay away' and I said 'that's probably because*

*they don't know what to say, and how to approach it' but he said 'yes, but if they're real friends, they come no matter what'*

*Karen, age 50*

Sometimes people who were ill did not want to see other people, either because they did not want to talk about their illness or, especially near the end of their illness, because they did not like the way they looked or did not have the energy to socialise. The quote below illustrates this.

*.....".....just before they died, because they were so thin.....and they're aware of how they look, they don't really want people to see them.....maybe they want people to remember them as they were ...it's hard for them to have a conversation.....it just exhausts them"*

*Jane, age 40+*

Voluntary groups and services were also useful supports. Some groups were specific to a disease, some were more general; all provided a place where people could meet others in the same position and feel supported with the practical aspects of their illness. These groups could also be a support to those who were bereaved.

#### ***8.2.7.2 Social needs and experiences of people who have been bereaved***

All the participants talked about bereavement, which fell into three fairly distinct stages; the immediate aftermath of a death, e.g. arranging a funeral; the grieving process; and long term adaptation to being without the deceased person, such as coping with living alone and finding new roles in life. During all of these times, people who had been bereaved could feel very vulnerable and very much appreciate the support of their family and friends.

When a person was first bereaved they were usually distressed, in shock and had a lot to organise. Participants described how this difficult time could be made easier by the support of other people. Family members could often comfort support one another; this view is illustrated in the quote below.

*"...families, most families, pull together.....I think in general, that there is plenty of comfort and love going around"*

*Karen, age 50*

However, death could also be a time of family conflict as ‘skeletons come out of the cupboard’, as another participant, who had a lay funeral ministry, describes in the quote below.

*...”....Oh dear, can you get into family rows!... all the family feuds come out, skeletons come out of the cupboard, all sorts of things..”*

*Andrew, age 50+*

Friends and neighbours could also provide support, and the participants seemed keen to do this where they could. Several described the value of practical support, and the need to take the lead, rather than asking the bereaved person what they can do. Providing cooked food was often mentioned, as was helping with practical tasks such as organising the funeral or registering the death. The quote below summarizes this idea. Where people had offered help such as this, it had usually been appreciated and accepted.

*..”If people say..... “what can we do”?..... I think their brain’s a bit cabbaged at that point, they’re like, “Well, there’s nothing”, so you need to step in with er, “I can do this” or... just take a plate of food round, so that they don’t have to sort of stop and think, “Oh, I’m sure there’s something I want done, or I need done”...”*

*Stephen, age 58*

Friends and neighbours could also offer their condolences and words of comfort, although often there was little that could be said, especially by a person who was not very close to the bereaved, or if the death seemed particularly tragic, e.g. a young death. In the quote below, one participant described how at a friend’s funeral she could find few words, but felt this was appropriate.

*...”...I did have a friend, who was a good deal younger than me who died....and I went to her funeral, and when I saw her husband, I was absolutely speechless, so I just gave him a hug and said, “John there nothing to be said, is there?”, and he said, “No there isn’t”.....no words would touch that sort of central point of loneliness”*

*Mary, age 70*

Another, younger participant described using exactly the same approach and how it had felt inadequate.

*...". I didn't know what to say to my, one of my old best mate's older brothers, when he took his own life..... I just didn't know what to say, so I just said, "Dan, there's no words, I'm sorry" and, "I'm here now don't worry". And then you feel stupid..."*

*James, age 30*

Sometimes it helped to share memories the deceased, although one participant commented that the actual words spoken may have little impact on the way somebody feels about their bereavement. In the first quote a participant describes a conversation he had at a friend's funeral with the friend's mother, and in the second he talks about his own bereavement when his grandfather died.

*..."At Dave's funeral...(I said).. "Do you remember when we went to Summerslam, and watched wrestling at Wembley stadium?", and you know, I talked to her and she laughed her head off, she was crying, but we were laughing.."*

*...."....if you want any perspective from people grieving, I can think quite clearly now about that time and I wasn't really bothered what people were saying to me. I wasn't really taking it in.....I can't actually remember any, anything that anyone said that actually helped me..."*

*James, age 30*

Recently bereaved people often found that people in their social network, sometimes including close friends and family, avoided them. This could be very upsetting and difficult, although they understood that it was due to people not knowing what to say. They also experienced people who continued to socialise with them, but avoided talking about the bereavement or the deceased person. This is described in the quote below.

*..."....my sister... lost a child...and she had best friends that just didn't contact her, at the funeral they turned up, didn't give her any eye contact, left afterwards. My sister was devastated.....and I had it as well, with (partner's death) ...my youngest sister, who I'm so so close to, she was just so distant with me.....I felt let down by her... but as the time's gone by... I understand ....she couldn't do anything else...."*

*Jane, age 40+*

Where the people around them avoided the subject of a recent bereavement, it put the burden on the bereaved person to manage their discomfort.

*...”....some people are very comfortable and ask you questions about it and others don’t know what to say, so they don’t want to go there. You’re almost having to manage their discomfort as well as your own bereavement...”*

*Margaret, age 64*

Although all of the participants wanted to and had supported other people in their bereavement, some described reaching out to somebody who had been bereaved as ‘a risk’, because of the possibility that they might say the wrong thing. The majority, as illustrated in the quote below, were of the opinion that the ‘risk’ was always worth taking, as it would be better to say the wrong thing than to avoid somebody.

*.....”....I think it’d be kinder of them to confront you and say something even if they don’t get it right, you know, just to say, “Look I am here”.....rather than just ignore or dismiss it, because that is painful.....”*

*Jane, 40+*

Two participants suggested that it was possible to say something so inappropriate, it would be worse than saying nothing. The quote below gives an example of this.

*...”...her husband...(was)..hit by a bolt of lightning and killed...he’d got four kids under the age of 18..... and they did the funeral .....and somebody came up to her on that day at the graveside and said, “Don’t worry, you’ll find somebody else”, and, unbelievable!....”*

*Sarah, age 37*

People who had been recently bereaved also appreciated written information, both on the practical aspects of what needs to be done after a death, and on the emotional aspects of what to expect to feel after bereavement. Participants reported that leaflets provided by ambulance trusts, hospitals, hospices etc. usually contained this information and were considered to be very helpful. However, participants who had not been bereaved, and had not seen such information, often worried that they would not know what to do when somebody died.



After the immediate aftermath of the bereavement and funeral, people who had been bereaved continued to need the support of those around them. Often, family members could be a great support, and a death might bring them closer. Sometime, however, different family members might grieve at different times and in different ways, and therefore be unable to support one another as well as those further from the situation might. In the quote below, a participant who was a counsellor in a hospice explained this in theoretical terms.

*...”...when we’re really in our own grief, we can’t really be there for somebody else in their grief. And when we’re talking about the same person..... if we’d lost me mum, erm, and I’m with my sister, if I’m trying to support her, and offer strength to her, then when she’s talking about her mum it’s going to trigger my own grief and I’m going a fail to support her..”*

*Peter, age 50+*

After the funeral the bereaved are continuing to grieve and usually need opportunities to talk about how they are feeling, and about their memories of the person who has died. They also need to continue their social life, which, in the case of people who have lost a spouse or partner, might be difficult. Friends, neighbours and others in the community could help by continuing to socialise with them and provide a ‘listening ear’, as described in the quote below.

*...” ....people tend to stop visiting and stop going round.....they want you to keep going round....and then just leave it open. If they want to talk about their loss, that’s okay, and nine out of ten they do.....they want to talk about their memories that they had from when the person was alive...”.*

*Janet, age 58*

Others might support the bereaved person to continue their social life.

*.....”...the steward....came to me and said “You’ve done barmaiding haven’t you...will you come and do a few shifts?” ....he was making time for me, to get me to keep my head above the parapet and a say, “Hello I’m still here”, you know....and he gave me confidence to go back out.....and to let people know that...I would talk about John and loved it...”.*

*Margaret, age 64*

Often the best people to support those who had been bereaved were others in the same position. In the quote below, a participant who lost her husband about three years ago describes the empathy and support she received from another widowed friend.

*...”...she was the one that said things to me, like er, “You’ll miss his voice you know”, and then ....I says, “How are you doing?”, “I don’t know”, she says, “Just sometimes it feels like yesterday and sometimes it feels like a long time ago”, so I knew I was on the right track...”*

*Margaret, age 64*

This shared experience also extended to more formal bereavement support groups. Participants working in palliative care settings spoke about the groups ‘normalising’ grief and ‘giving permission’ to talk about it. In the quote below, a participant who first attended and then took over the running of a bereavement support group describes what it was like. These groups were not for everybody, either because of work or family commitments, or because they did not think it would helpful.

*...”...she said, “I thought it was going to be so cryey cryey saddy like all this counselling that they’re big on” she said, “it’s nothing like it”.....I make them laugh, I always throw something into the ring to keep them going.....she lost her daughter three years ago.....and she’s still absolutely devastated, but she absolutely relies on the group, because when she first started with the group ....she was a mess...”...*

*Margaret, age 64*

Employers and colleagues could also play a significant role in supporting (or not) somebody who had been bereaved. One participant described how helpful her employer was in taking the pressure off her for a few weeks after her partner died, while another, showed in the quote below, describes how people who are bereaved within her organisation are pressured to go back to work before they are ready.

*...”...you get 6 days...leave, if your husband dies, or your wife dies. If it’s your parents.....you can get one of those six days.....there’s not time to grieve, and if there is, it’s interfering with work, isn’t it?.....I think if your establishments aren’t encouraging people to grieve and to be allowed to grieve.....they’re going to be constantly grieving while at work ...”*

*Sarah, age 37*

Participants wanted to support friends and relatives who were grieving, although some were unsure how they could help, or whether they could. This view is illustrated in the quote below. Some respondents who had been bereaved commented that some of their friends had not made the time for them.

*...”...when you’re talking to someone that’s grieving, I don’t think I’ve got, I’d like to think, but I don’t. I don’t have the tools...”*

*James, age 30*

Five participants described how some people who were bereaved could be very difficult to be around and seemingly impossible to help. They might grieve and talk about the death for years, or become very angry. In three out of the four cases described, the bereaved person had lost a child. Occasionally it can be so difficult for the people who try to support people in these states that they might be hesitant to try to support other people in the future. The quote below illustrates this theme.

*...”...some people stay within their grief for years... they need to grieve, again and again.....but then I think if you’re a friend of somebody who’s constantly grieving for years.....you’d want to tell them, “Pull yourself together and get on with it”, or you’d distance yourself and not be their friend...”*

*Sarah, age 37*

Sometimes friends might struggle to support somebody because they are also grieving, but to a lesser extent. This might be particularly important in the case of a young death, which is often harder for everybody to come to terms with. This is described in the quote below, from a participant who had experienced the death of both her 19 year old son and her 90 year old father.

*...”... I think if someone dies quite young family feel a bit unable to support the bereaved, I think it’s easier if it’s an older person like my dad was 90.....so you don’t expect a 19 year old to die, where you expect a 90 year old to die....and you, know, you’ve got all your own sadness and emotion to cope with as well as comforting someone who is bereaved really”*

*Ann, age 65*

Social and emotional support was also helpful as people start to adapt to living without the deceased person, and perhaps to living alone. In the two quotes below, one participant, who had been widowed for about three years, talked about one

friend's understanding and another friend's lack of understanding of what it is like to live alone as a widow. Again, the theme was of empathy.

*...“(she) will say to me.....”What did you have for your tea?”, “Oh I had a bowl of cereal”, “Yes it’s awful isn’t it..... I’ve been making myself a pan of stew and I’ve divided it up into three portions and put it in the freezer”, and we’ve had a discussion of it, erm....because she empathises and she understands.*

*...”...she’s not willing to sit and listen about my lonely side, and I don’t want to inflict my loneliness on anybody, but she never asks me...”*

*Margaret, age 64*

People who have lost somebody close might enjoy talking about that person for years afterwards, maybe even the rest of their life, including with younger members of the family who might not remember the deceased, as described in the quote below. This was believed also to be a gentle way of making young children aware of mortality.

*...”I’ve got a grand-daughter and she’s only three and a half .....I’ve talked a lot about her granddad ... she knows her granddad died and different things and I’ve taken her to the cemetery and things like that”*

*Susan, age 50+*

Participants described how, especially where bereavement coincides with old age and decreased mobility and health, some people who lose a spouse or partner never regain their social connections and become quite isolated and vulnerable. Men were believed to be more vulnerable to this than women. In the quote below, a participant describes the situation of a man in his local community, who he encountered as part of a voluntary project.

*...”...I went to see this little old guy ....I used to take him half a bottle of scotch as well as a box of chocolates.....”Come in” he says, “I’ll get two glasses”. The glasses were filthy, the house was filthy, his suit was shiny where he’d wiped his hands down, and he’d never taken it off. And I said to him, “When did your wife die?”, he said, “Oh, 20 year ago”. You see, and he just hadn’t looked after himself since...”*

*Robert, age 69*

## **8.2.8 Compassionate communities: how communities and volunteers can support people**

### **8.2.8.1 Current activities**

Participants in three interviews described three different informal and semi-formal 'schemes' which they knew of and which supported local people who were ill, bereaved or isolated. All three relied on just one or two people for their continuation.

One participant, who had lived in the same area for many years, described activity he was involved with on his housing estate, which acted as a sort of neighbourhood watch and voluntary social service in one. He describes this in the quote below.

*..”.....if anything happens on this estate, either Margaret or Eric will let me know or vice versa, I will pop round and just see them ...Margaret’s the best security you can have, I’ll tell you.....whatever goes on on this estate she sees..... but she’s good hearted and she always sees one or two people every day who are house-bound....they never see anybody else”*

*John, age 72*

Another couple, who lived in a small village, often visited and took food round to people who were ill or bereaved, and had become known for that. Other people in the village had begun to emulate their activity.

*...”.....(we) started to do the food, erm, when people were ill or bereaved, and now others have started to take that over, locally....it’s gone beyond the village.....we knew our neighbours, superficially.....He was seriously ill, and they knew enough to give us a call, so we went over.... it’s what we do...it’s what everybody does actually, it’s not just us...”*

*Stephen, age 58*

Another described a slightly more formal scheme, run by the local Rotary club, to which some individuals added their own touches. The 'knock on effect' described by this participant was improved household security for a household of two elderly women who he visited. However, this scheme finished when the local district nurse, who supported it, left. He describes this project in the quote below.

*....”...we had what we call ‘choc and chat’...we took chocolate and chatted to them at Christmas ..... the district nurse gave us a list of people who were*

*on their own, er, great knock on effects .....we've stopped doing it now because we lost the district nurse, that system is not there anymore.."*

*Robert, age 69*

Churches and faith communities also often tried to look after members of their congregation, and ran voluntary projects aiming to reduce isolation in elderly people.

*..."...we try to have...spotters to see if anybody that we should know about it missing, you know, try to find out.....what's happened to them....."*

*Andrew, age 50+*

Local hospices provided support services, run by volunteers, for people who are bereaved. One described the activities offered by her local hospice, where she volunteered. None of the participants had used or volunteered on one of these support systems; they knew of them through their connections with the hospice.

Close neighbours often 'looked out' for one another. This was not limited to those who were dying or bereaved, but to all who were vulnerable in some way. However, availability of support from neighbours depended on who the neighbours were, the type of neighbourhood, and how long a person had lived there. The quote below gives an example of neighbours looking out for and supporting one another. A common theme in support from neighbours and community is the need not to appear 'nosey'.

*..."We have Mildred and George across the road.....we look out for each other... it's not nosey, if...the curtain was still drawn, er, when I know they usually open, I keep watching and then I breathe a sigh of relief when they come open.."*

*Patricia, age 74*

#### **8.2.8.2 Participants views of the concepts behind compassionate communities**

In general, there was support for the idea that friends, neighbours and volunteers could do a lot to support people who were dying, caring, or bereaved, as suggested in the first quote below. However, many people were of the opinion that not everybody, perhaps only a minority of people, had sufficient motivation and empathy

to support people effectively, as evidenced by the second quote. The majority thought that no amount of training or information would change that; although some thought it might be worth a try.

*..” .....care.....comes from whether you care for other people, and.....you can care for your neighbour.....buying the sugar and just sitting with them .....the welfare state is not there to provide what I would class as pastoral care.....voluntary organisations are probably best, in, in actually providing care and support for others...”*

*Linda, age 60+*

*...” we find that an awful lot, that people really are, ‘bum bum bum’ with their own lives.....there’s only a few others that really can sense when there’s something that’s not quite right.....maybe it’s something that can be taught to people, erm, I don’t know, how do you do that? I mean you either are that sort of person or you’re not, really aren’t you?*

*Patricia, age 74*

Some participants believed that, despite this, there were enough people with the motivation and supportive communication skills to adequately support everybody who needed it. In addition, talking and listening were not the only skills which could be used to support others; practical skills could also be useful. These ideas are summarized in the quotes below.

*...”...I think there are some very skilled people out there who will listen really well and who despite their own discomfort will go there for somebody else...*

*....”...my brother’s very practical, he’s great at practical stuff, I’m not as good at practical stuff, I’m brilliant at holding a safe space so they can talk about stuff that matters, he’s not so good at that...”*

*Julie, age 40+*

Some commented that not all vulnerable people, who might benefit from more social support, fitted into the categories of dying, a carer for somebody who was dying, or recently bereaved. Other groups included those with learning disabilities, dementia, mental health problems, or limited mobility. The quote below describes a situations where a person was vulnerable and in need of support mainly for other reasons.

*...”...I supported this 24 year old (with learning disabilities) with um, organising his mum’s (funeral) service.....she’d been in Liverpool for three months and he’d been there on his own in a house and he’d had no hot water, no heating, cos he didn’t know how to, who to ask”*

*Deborah, age 50+*

### **8.2.8.3 Individual barriers to effectively supporting people**

#### **Lack of confidence or experience in talking about death and bereavement**

It was a common belief people sometimes did not know what to say to people who they knew were affected by life-limiting illness or bereavement. This lack of confidence led to anxiety that might lead to avoiding people who had recently been bereaved, avoiding talking about the person who had died, or saying something inappropriate. A few participants commented that they themselves would not know what to say to somebody who had recently been bereaved, or that what they would say or had said in that situation seemed inadequate. Some believed that only certain professionals would know what to say, because they had the experience or training that other people did not. The quote below illustrates this lack of confidence.

*....”.....you don’t know what to say really. I think, I don’t know how many people would be good in that situation unless it’s somebody in the nursing profession who was used to death..”*

*Joan, age 75*

This suggests many people might misunderstand the support that people who are bereaved need, as the general consensus was that it did not really matter exactly what was said, what was important was to make contact and be there for somebody. “I’m sorry for your loss” is therefore probably often a perfectly adequate message of condolence.

It also appeared that, where people did not have this anxiety, or when they forced themselves to overcome their own discomfort, comforting others was often instinctive. Many participants described how they found talking to somebody about the other’s bereavement much easier than they expected. One participant described an unfamiliar situation where he had to break the news of a death to the deceased person’s mother; and although he thought it would be difficult, found that he instinctively knew what to say and do. In the quote below, a participant describes



how he had to take courage to talk to his friend's mother at the funeral, but the conversation had gone well.

*"...I thought I'm not, I'm not going to avoid Dave's mum.....and you know, I talked to her and she laughed her head off, she was crying, but we were laughing.."*

*James, age 30*

People might also be afraid to talk with somebody about their illness or bereavement, again for fear of saying the wrong thing; for example, was it okay to ask, "How are you?"

Participants suggested that healthcare staff could also lack confidence in talking about death, which might sometimes be worse in situations where the aim is usually to cure the patient. They also run the risk of getting a bad reaction from the person they are trying to support. However, participants who worked in palliative care suggested that it was worth the risk, because most patients were able to 'deflect' conversations that they did not want.

One participant, who worked in palliative care, suggested that many people found silence uncomfortable. This could affect communication where the person was ill or bereaved may also not wish to converse, or may need time to collect their thoughts. In reality, silence might sometimes be exactly what is needed, as described in the quote below.

*..."I think as well some people find that silence is uncomfortable.....to sit down and cope with it being silent, and a lot of us struggle with that, especially around the difficult topics, you know.....so sometimes, it's giving them the silence..."*

*Sarah, age 37*

People who did not meet with the bereaved person on a regular basis sometimes did not know how to make contact after the bereavement; how to initiate the conversation. Several participants suggested the solution was that when going to somebody's house, to always offer a gift. In the quote below, a husband and wife together explain why.

*..."(wife) it's difficult to go, but if you always go with something in your hand, you never get rejected.....it's very difficult to go and knock on the*

*door.....(husband) because you can't open a conversation on the doorstep...about bereavement, too easily.....if you go in with something, you can start positively..”*

*Linda and Michael aged 60+*

### **Lack of knowledge about the grieving process**

There were several common misconceptions, or areas of ignorance, about the process of grieving after bereavement.

One was that it was unhelpful to talk with people who were bereaved about the person who had died, either soon after bereavement, or after a certain period of time. In reality, people generally enjoyed talking about deceased family and friends, however recently they had died. In the quote below, one participant described how she had to let people know that it was fine to talk about her late husband, and how glad his old friends were to be able to talk about him with her.

*..”....I had to sort of talk about John to prove it.....and if I was with his old friends, you know, saying, “John did that, didn't he?”....they were relieved that I would say it.....”*

*Margaret, age 64*

There was also a misconception that support for people who are bereaved should have a time limit, after which they should be expected to ‘move on’, a view illustrated in the quote below.

*..”...(support for people who are bereaved) ...doesn't want to be continuous, you know, it wants to be for er, a period of grieving as it were...you've got to move on.”..*

*George, age 85*

In reality, people could be ‘hit’ by a loss, and need the support of their friends, at times that they did not expect, and at times after when people around them expected them to have ‘moved on’. One participant described his own experience, while others described how they had seen it in others. In the quote below, a participant who is a counsellor in hospice gives a theoretical view of the process, which was consistent with that described by other participants.

*...”...immediately after a loss, it is so raw and painful....there’s a shut-down.....only of the person....directly hit by the bereavement.....everybody else around them thinks they’re processing, but they’re not.....the processing actually comes a few months later.....they then start hitting ..... the reality of the loss.....(and) at that point.....everyone around them has....moved on ....”*

*Peter, age 50+*

Participants themselves often commented that they or others did not have adequate knowledge of how to effectively support somebody who had been bereaved, or that, with the hindsight of knowledge they had gained since, they would have been able to support somebody better than they had. This extended to people who were bereaved themselves, as knowing what was ‘normal’ in bereavement helped them to cope and to guide the support of people around them. In the quote below, a participant who had attended a training course on bereavement and grief, described the wide range of ‘normal’ grief reactions that people might experience, and how useful it was to know about this.

*...”...even just knowing what is normal.....if you’re angry, at the person who’s just died.... that’s a perfectly normal reaction, erm, or you just lose complete interest in anything and everything .....that can be a normal part of the grieving process..... some days or some hours or some minutes.....you can be laughing and joking, and the next minute you suddenly find that it’s really tough to do anything.....”*

*Julie, age 40+*

### **Fear of upsetting or burdening people**

Participants suggested that some people hesitate to ask people about their bereavements for fear of upsetting them, or of triggering outpourings of emotion. None believed that this was a real risk, or that triggering emotion was necessarily negative, but some perceived this fear in other people. The quote below summarizes this view.

*.....”..... they are uncomfortable with these sorts of emotions, but...it’s normal....and actually people are frightened when somebody starts to cry*

*when it's nothing to be frightened of really, it's just a normal part of the process"*

*Julie, age 40+*

In addition, some people who have been bereaved or who are ill may not admit to needing support themselves, as they do not want to upset or burden other people. In the first quote below, a participant who worked in a hospice shares her observations. Not wanting to burden others could occasionally lead to secrecy about illness and prognosis in an attempt to protect the relatives, although this often actually had the opposite effect, and meant that family members were unable to support one another.

*..." I have one gentleman at the moment and his prognosis isn't very good.....he said he doesn't like to burden his wife with his thoughts because he thinks she's got enough to cope with, with looking after him"*

*Karen, age 50*

### **Traumatic bereavement**

Occasionally people who were bereaved became so distressed by it that they were unable to talk about it at all, or talked about little else for years, or became ill, or became very angry. This might happen more frequently in case of the death of a child. These extreme reactions made it difficult for the people around them to offer support, and sometime made it difficult for the bereaved to talk about other deaths in the future. In the quote below, a participant describes how her mother was, following the death of her young brother.

*..."while she was in hospital, John died.....and....it was never spoken of, John was never spoken of.....my mum would not talk about it, she completely lost it.... she never really recovered from that..... (when) my dad was very ill...she just wouldn't talk about anything..... and we ....couldn't get through to her, when my dad died.....she just cut off .....then when my mum died, I mean, again, we couldn't talk to her...."*

*Patricia, age 74*

## Isolation

Some people had no access to support from friends and neighbours because they lived alone and were isolated, not seeing any friends or neighbours, as illustrated by the quote below.

*... " ...when I was in hospital.....there was people in there.....that had never seen a neighbour.....they wanted to stop in hospital because there was somebody like me to talk to.....two elderly gentlemen, one on each side of me, you know, who I used to chat to, and if they knew there was a good chance of them going out, they became ill again.....one guy said, "I never see anybody". He couldn't get out of his house"*

*John, age 72*

### 8.2.9 Societal barriers to talking about death

#### 8.2.9.1 Hidden death

Participants talked about how death tends to be hidden away from everyday life, and many people do not experience close bereavement until they are middle aged themselves. This leaves a large proportion of the population with little experience of death, and therefore little experience of talking about death. This view of death as hidden is illustrated in the quote below.

*.. " ... it's become something that's put away, it's like with the elderly, they get put in a nursing home, whatever.....say.....sixty years ago, maybe a bit longer, it was much more in the family and death was much more part of life.... people are born, people die, and it was all in the house and that was just how it was, whereas now, you're just sort of, moved away.....hidden...and I think that makes it scary for people"*

*Karen, age 50*

#### 8.2.9.2 A 'taboo' on talking about death?

Several participants talked about a 'taboo' around death, as in the first quote below. The Oxford Online Dictionaries [187] defines a taboo as: "A practice that is prohibited or restricted by social custom". However, the way that the apparent 'taboo' was defined by participants varied considerably from this definition. Most

often it referred to people not feeling comfortable talking about death and dying, or being afraid to talk about it, as illustrated in the quote below.

*....” ...death’s a big taboo subject .....when you kind of mention death or anything to do with that you know it’s kind of their attitudes are so much different and I think it’s a shame.....”*

*Susan, age 50+*

Occasionally it referred to not wanting to contemplate losing somebody through bereavement, as in the quote below.

*.....”you’re never ready to lose someone who’s that close to you, so that for me makes it an automatic taboo area....”*

*James, age 30*

One participant, while not actually using the word ‘taboo’, made a comparison from the Harry Potter stories, suggesting that some people felt it was wrong to say the word, ‘death’. This is shown in the quote below. In the stories, the hero, Harry Potter, speaks of the main villain, Lord Voldemort, using his name, while the majority of characters refer to Lord Voldemort as, ‘He who must not be named’.

*..”...it’s like saying the word, ‘Lord Voldemort’, isn’t it? ‘He who must not be named’ ..... they’re just scared of the word, they don’t want to discuss it, they don’t want to bring it into the house...”*

*Sarah, age 37*

One participant used the word ‘stigma’ in the same way that others used the word ‘taboo’. The Oxford Online Dictionaries defines ‘stigma’ as ‘A mark of disgrace associated with a particular circumstance, quality, or person’. This suggests that to some people to die or be in the process of dying might be seen as socially unacceptable somehow.

*...”...I was brought up with this thing about stigma about dying and you don’t talk about it..”*

*Patricia, age 74*

One participant expressed the view that death was not actually a taboo subject, although some people might think it is. This is shown in the quote below. This

suggests a common unfounded feeling that other people will not approve of a person talking about death.

...”...it’s quite normal to talk about it, you know, it’s not taboo, it, it needs to be discussed....”

*Jane, age 40+*

However, there were three other themes that, although not linked by participants with the idea of a taboo, that more closely matched the dictionary definition of a taboo.

The first is historical custom, where talking openly about death has not been the norm in the past, in some families at least, and therefore might still feel ‘wrong’ in some way. Many of the older participants suggested that when they were young, people were less open about death than they are today. This perception cannot be assumed to be factual for society as a whole, but was a strong theme within the research sample. Some participants linked previous generations’ lack of openness about death to lack of openness about other unpleasant or socially censured phenomena, which were described as being ‘swept under the carpet’. Society was thought to be becoming more open about these things, which was considered a good thing, and therefore society should and could also become more open about talking about death. This view is illustrated in the quote below.

...”...*A lot of things in the past were swept under the carpet, you know, and it’s not that sort of generation now, is it? It’s a new, open, and I think this is what this is, it’s more open...*”

*Jacqueline, age 55*

The second theme related to a taboo, presented in a previous section, is a sort of superstition that talking about death can bring death forward. This implies there could be some adverse consequence to talking about death, and presumably it would meet with the disapproval of people with this belief.

The third theme is the common description of death as a ‘maudlin’ or ‘morbid’ subject, or as subject which others might find morbid or miserable. This makes it an unsuitable subject for social situations where people expect to be cheerful and enjoy each other’s company, and can lead to difficulties ‘finding the right moment’ to have

specific conversations with family members, especially where families do not meet often. This is illustrated in the second quote below.

*".....I thought, "I must bring it up with my stepdad, and with my dad and step mum", but...well there didn't seem to be a right time..... it was so nice and there was loads of laughter going on and it was lovely and .....somehow the right moment just didn't seem to be there"*

*Karen, age 70*

#### **8.2.9.3 Protecting children from the realities of death**

It was perceived that, in modern North European generations, children have been protected from the realities of death. Children were excluded from hospital bedsides, funerals, and even sometimes from hearing that a pet had died. This was viewed as something that would, in the long run, result in people growing up more ignorant of and fearful about death. The quote below describes children being excluded from the hospital where their grandmother was dying.

*...".I was 13 or 14, and I remember my aunts and uncle, they wouldn't let my cousins, because they were one or two years younger than me, they wouldn't even let them to the hospital when my nan was ill, because they wanted.....them to remember her as she was, not in the hospital and poorly"*

*Karen, age 50*

Participants were divided over whether this was getting better or worse, some participants saying that people were talking more openly with their children, and with children in school, while other saying that children were becoming more over-protected with regards everyday reality. One participant suggested that child protection concerns may prevent adults from effectively comforting children who had been bereaved and that this might have a long-term negative effect.

#### **8.2.9.4 Behaviour not catching up with changing needs**

Some participants suggested there might be more need to plan for end of life than there was in the fairly recent past, when there were fewer choices, and that behaviour might not have caught up with this increased choice. In the past, funerals would often follow a traditional pattern; there was less need for people to state their wishes, because family organised the funeral according to tradition, or were directed



by the church. Fewer people owned their own homes, homes were less expensive, and families were often less complex. Wills might therefore have been simpler and less necessary. The quote below illustrates the views of how funerals were organised in the past.

*....”...I remember when my grandma died, my mum and dad didn’t know anything about what they wanted, it was just what they do, isn’t it? They just bury her and sort out her stuff and do what they want basically, with respect, you know...”*

*Jane, 40+*

#### **8.2.9.5 The impact of geographically mobility**

Participants often suggested that it was difficult to support people around them because they did not know many of the people who lived close to them. This was due to the nature of opportunities, how residential areas are arranged, and lifestyles, and was perceived to have changed over time, with people knowing fewer of their neighbours and interacting with them less now than in the past. There is also variation from area to area, with small villages generally having a greater feeling of community than larger conurbations. These variations by time and place are described in the quote below.

*...”...the key was always in the front door, and your neighbours would come in, and if your kids came home from school they would nip in to look after the kids, erm, if you were ill there was always somebody there to come and look after you. That’s non-existent now...”*

*John, age 72*

Families often live a long way apart, whether to take up opportunities or out of necessity, which also contributes to the loss of community and makes it more difficult for family members to look after one another.

There was also a perception of differences according to social class, although this might represent perceptions of people who were different to the participants. The general theme was that both very affluent people and people living in deprived or dysfunctional circumstances might not have the time or inclination to think about

other people. There was also a view that in affluent areas, people often want to appear self-sufficient, and might be less receptive to receiving support from others.

However, this lack of geographic community did not mean that people were not connected with others, just that the people in their social circle were not necessarily where they lived, as described in the quote below.

*...”...we all live isolated lives. I mean you look at a road like this...I know the people who live round and about, but the rest of them, I don't know who they are .....they will have good peer groups, and groups of friends, but they won't necessarily be where they live. They are maybe to do with work, with interests and various things..”*

*Andrew 50+*

The general view was that geographic mobility was still increasing and that opportunities for people to meet their neighbours were decreasing. Therefore natural communities based on geographical proximity, and their associated support systems, might continue to be lost.

#### **8.2.10 Suggestions for activities to encourage planning for and talking about death**

Participants were asked their ideas for activities to make it easier for people to talk about death, dying and bereavement. A wide range of ideas were put forward, both by participants who worked or volunteered within palliative care or the CLWDW programme and those who did not. Participants generally put forward activities to address specific barriers that they had identified.

In general, participants were optimistic both that society was becoming more open about death, and that people were becoming more knowledgeable about the need to plan. Parallels were often made with other previously 'taboo' subjects which were no longer taboo, especially talking about cancer, and with other public health or education campaigns which had been successful. There was also a perception that things were already happening that would raise awareness. The quotes below illustrate this optimism.

*“.....there's always,...something dropping through the door about making wills.....or there's something on television.....I think psychologically it's getting through to people.....it's going to be a long*

*slow process but I think we're going to get perhaps another 15 years it'll be the norm. And I mean it was like giving up tobacco wasn't it, I mean look how they've had to really hammer that away but now you are very much a minority, aren't you, if you smoke"*

*Patricia, age 74*

Participants described both the overall approaches that they thought should be taken, and the individuals and organisations which they suggested might be involved.

#### **8.2.10.1 Overall approach**

There were two overall approaches described, population level and individual level, both of which involved many different activities and target groups. The approaches were sometimes described in terms of distance from death; with, in general, population-level approached targeted at people who were well, more targeted individual work occurring closer to death.

The first approach was population-level, raising awareness and normalising death as something that should be planned for and talked about, and about which relevant information was available. This approach included both simple information messages and more subtle interventions designed to open up discussion about death. Common analogies were of 'planting seeds', and a 'drip drip drip' effect, as shown in the quote below. The general idea was that once that seed had planted in some people, it would develop, and then those people would talk with other people, who would talk with other people, etc.

*...."....once you get a little snippet of information given to you, then it opens up your enquiring line to go further, I think.....a little snip, here and there, drip drip drip of information"*

*Christine, age 65*

The second approach was providing access to relevant information, advice, and opportunities to discuss options for end of life planning. This approach was more targeted or individual, although the effects would still be expected to ripple through the population. It included clinical settings, but was not limited to this context.

### 8.2.10.2 Specific ideas

#### Children and young people

Many participants suggested that death should be a topic within children's education, to help them become more confident about talking about it, and indirectly encourage parents to talk about it. Death education was sometimes compared to sex education or health education, which some older participants talked of missing out on in their school days. It was viewed as an opportunity for older school children to discuss issues around death and dying, while they were still in a group situation.

The general theme was that education should start as young as possible and continue in different age-appropriate forms up to college age. A number of different issues and ways of covering them were suggested; e.g. religious education could include the death rites of different religions; history could include oral histories of older people; and informal education and discussion about bereavement could be included within school assemblies and pastoral classroom time. Older children and young people might receive more specific education on coping with bereavement and loss, or on managing home finances, including making wills.

One participant, who worked as a secondary school RE teacher, described the work she did with her pupils, and their positive reaction. The work she described exactly mirrored ideas suggested by other participants and is shown in the quote below.

*"...we do discuss death and the afterlife and what some religions believe, it does give me an opportunity...I'm also responsible for some of the assemblies, so again, especially when I know somebody's lost, erm, a relative, it's quite easy to sort of just slip it in and discuss in a way that makes it okay...our kids are quite open to it....they're also very sympathetic when...one of the others has lost a relative or somebody close.."*

*Janet, age 58*

Other participants suggested that parents could make a difference, both by talking more openly and allowing children to see more, for example by allowing children to go to funerals if they wanted to.

## Television, radio, internet and other mass media

A common suggestion was to use television or radio to reach large numbers of people in a small way, as part of the 'drip, drip' effect. Television, radio and internet broadcasts were believed to have potential to raise awareness of issues relating to death and help to normalise death. Formats could include a storyline within a soap opera or drama, a documentary or article within a regular documentary series, or some sort of 'advertisement'. A common theme was of something that would 'get people thinking', or 'get people talking'. The quote below summarizes this idea.

*..."...well if you think about it...they're very good at reporting disasters.....but they don't help people how to talk to people, giving information. Much can be done in that direction, make a programme about it.....and once you start talking, you carry on talking..."*

*David, age 59*

Some suggested that current television and radio programming was missing opportunities to include themes related to death within programmes which people already like to watch. For example, soap operas could include storylines of people recovering from bereavement, and health documentary series could include items on terminal illness and death. It was also suggested that people in the public eye might draw attention to issues relating to death. Comedians could also play a part, using humour. Some thoughts on this are presented in the quote below.

*..."...one of the best things that came out of Jade Goody getting ..... cervical cancer, was the fact that, you know, they followed her round and .....we all love to watch a celebrity ..... and they showed it, they showed all of it.....right up to the point where she died.....she was a nice gobby person so it worked well.....things like that open up people ideas to what can be said and what can't be said and...who to get support from "*

*Sarah, age 37*

## Awareness-raising and education by Hospices

Knowledge of hospices and palliative care was suggested to help reduce fear of the unknown and increase awareness of the options available. Hospices already often have good links within the community through their fund-raising activities, and their

awareness-raising work could be linked to this. It was also suggested that hospices might also be able to contribute in other ways, including training volunteers and members of the public in how to communicate with people experiencing bereavement. In the quote below, a participant gives her views.

*...”I think perhaps if you had a film that you could do, you know an illustration of what it’s like in there.....what life’s like in a hospice.....the choir, we did a little fund-raiser for the palliative care centre and....I wasn’t the only one, who didn’t know what a palliative care centre was....so now we know what help we’ve got here...”*

*Christine, age 65*

### **Promoting access to information and information on end of life planning**

Several participants suggested it would be useful if people were able to access advice on end of life planning, whether they had a life-limiting illness or were well. This might be based within GP practices or libraries and include information leaflets but also access to personal advice if wanted. Several participants mentioned structured guides on issues to consider for end of life, and one suggested regular reminders from the government regarding wills, much in the same way as some people get regular reminders about tax returns. This is shown in the quote below.

*.....”...it’s a bit like tax returns, where you just can’t get away from them, sort of thing. It should be spun round like that. There’s maybe a, a once a year, you know, erm, death plan, or whatever, that you have to look at .....it sort of says, basically, “Unless you do summat else, all your money will go to the government....”*

*Peter, age 50+*

Two participants suggested that if free courses on end of life planning were made available for older people, similar to courses already available on planning for retirement, a few would attend and then pass some of which they had learned on to their friends and family. In the quote below, a participant likens this idea to a computer course she did.

*...”.. I’d never been on a computer then suddenly there were these courses that were free for elderly people to go on .....if you do the same thing, erm,*

*it's bringing it all the time to people's attention ..... it's not everyone my age knows computers ..... and I've got friends ..... "Can you come round and show me how to do shopping on-line?".....so I'm out there doing my bit because I had this free computer course..."*

*Patricia, age 74*

## **Workplaces**

Workplaces were suggested for intervention in two ways. Firstly, larger workplaces could work with external partners to provide information and perhaps subsidised services on subjects such as wills and funerals. Secondly, all workplaces could improve policies and support for employees who are bereaved, caring for somebody or facing a life-threatening illness, for example by giving sufficient bereavement leave, as suggested in the quote below.

*"...if your establishments aren't encouraging people...to be allowed to grieve.... they may go back to work and....be constantly grieving while at work....you know, it's more useful if they let you grieve..."*

*Sarah, age 37*

## **Information on bereavement and how to support friends and family who are grieving**

Several participants expressed concern that they or other people were not sure how best to support friends who had been bereaved, and suggested that it would help if information on this topic was made more widely available. Other participants suggested improving access to information on grief and bereavement for people who had been bereaved, so that they would know what to expect. The quote below gives one participant's thoughts on how to educate people on supporting people who have been bereaved.

*....."I think, er, a website or a, a pamphlet .....but something everyone can have, yeh. I think I would, or people being able to take part in courses on supporting, supporting friends with loss, supporting family members. And I think, I, I think I, I think that's important for, for a lot of people, yeh..."*

*James, age 30*

### Training for healthcare staff and volunteers

Several participants suggested training on end of life planning, communication and bereavement for health and social care professionals. There were two reasons to target this group. Firstly, health and social care professionals and volunteers often play an important role in supporting people who were dying and their families, and good communication with these people might facilitate good communication within the family. Secondly, people working in these types of roles might be easy to target and constitute a significant proportion of the population. It was hoped some might go on to talk with others, not working in health and social care, about what they had learned.

One participant suggested that it was not just the skills of individuals which helped, but the overall quality of services, as good quality health and social care can take a burden from families and help them to concentrate on the things that are important to them. One idea for healthcare staff training is presented below.

*... "I would love to be involved in giving a carer's perspective on what it's like to be a carer of somebody who is towards the end of their life, and what it's like when professionals do it really well, and what it's like when they don't do it particularly well, and what impact that can have on the carer, and the carer's the one that goes on living and has all these views and opinions about caring, about the professionals"*

*Julie, age 40+*

### Additional support for people who are dying and their families

Support services were suggested for people who had a life-limiting illness and were struggling to talk with their family about end of life issues that were important to them. A range of different people and organisations might be involved in this work, as described in the quote below.

*.... "....It's quite hard for a lot of families to talk about, I think if someone's ill, then a third person can get the family to talk about it....might be a vicar, but it might very well be a nurse, I mean it really doesn't matter who it is, but probably the family needs some support to, to sort of eek out the issues that are important and to talk about it in depth.."*

*Ann, age 65*



### 8.2.11 Comments about the CLWDW programme and events

The majority of comments about the CLWDW events and programme were on similar themes to those expressed via the questionnaires. Several commented on the importance of having good facilitators and a sensitive yet upbeat approach, as illustrated in the quote below.

*....it's good and the trainers.....they're obviously very knowledgeable about it, very much at ease, present it well.....if you've got a good presenter.....makes you feel comfortable..”*

*Jane, 40+*

A common theme was how attending the events prompted or triggered participants to take some sort of action relating to end of life planning. Some participants had been made aware of something that they had not previously thought of, as illustrated below.

*“I said to him, you know, “we need to talk about what you know” and he said, “Well you made an will..”, and I said, “Yeh, but do you know where it is?”, and he said, “No”. Cos it was one of the things that came up in one of the meetings, you know, people make plans, they make wills...and nobody knows where it is or what the plans are..”*

*Susan, age 50+*

One participant, who had attended a ‘How to’ workshop, described how it had given her the confidence to talk to family members about their end of life wishes, and how that had been much easier than expected.

*...”...since I’ve...done that training...I’ve learnt a lot from it, you know, I, I’ve gone home and I’ve said to like my eldest girl.....she’s married and she’s got a couple of children, I tell her about the training and stuff, and....end of life wishes.....I just like talk about it like I’m talking with you, it’s not difficult...”*

*Jane, 40+*

The only direct criticism of the events was that the format might be best suited to people who had a traditional family structure and no real social or financial hardships, as explained in the quote below.

*....."You talk about neat families and there's not a lot of neat families, there's a lot of dysfunctional families and a lot of, you know, lot of hardship around.."*

*Jacqueline, age 55*

Several participants described difficulties and potential difficulties in interesting people to attend CLWDW events, as in the quote below.

*...."I think I was the only person who turned up in response to the general diocese, you know, "this meeting's happening and it's open to anybody, so if you're interested come".....and I think, you know, when I mentioned I'd been on it, people think I'm a bit...peculiar, for going, you know, "What do you want to go on that for?", they sort of, nobody's actually said that, they just said, "Oh", and looked a bit puzzled"*

*Mary, age 70*

A potential solution to this, expressed by several participants, was to advertise similar events in the future in relations to looking after loved ones after death.

*.."...talking about death isn't one of the things that someone would go, "Oh there's a workshop about death, let's go".....I'm surprised that you got anyone turning up really.....but...if you sold it as, "Come to a workshop where you can learn how to make sure that your family and all your friends and people you love are going to be protected when you're gone"....it is a way to dress it up..."*

*James, age 30*

## **9. Qualitative interviews: Discussion**

### **9.1 Summary of main findings**

#### **9.1.1 General attitudes to death and talking about death**

Participants viewed death as a pivotal event for individuals, families and community, affecting people all ages, and as an important concern for all, especially in regards to bereavement. People wanted to prepare for own death to make bereavement easier for the family, cope as best they could with their own bereavements, and support friends and neighbours who had been bereaved. It was also important to have a good death, and to help others to have a good death and to die at peace. Consistent with other research findings, the natural death of an older person was generally accepted as 'part of life', whereas the death of a child or young person was less easily accepted [11].

Most people appear to be willing and able to talk about death and dying, and in certain circumstances, need and want to talk about it. This is also consistent with other research, which showed people were generally willing to talk about death [60, 138, 188] and often appreciated the opportunity when given [136, 189, 190] and with the experience of the public health workers delivering the CLWDE public health events, who found attendees willing to participate in discussions.

Most of the participants considered themselves to be comfortable talking about death. This might be expected in a study where participants had all volunteered to be interviewed about death and dying. However, the participants may not have been unusual in this regard – in both the questionnaire survey and other surveys [7, 8, 116, 117] the majority of respondents reported being comfortable talking about death and dying. Two participants said they did not like talking about death, although both described various relevant conversations they had had with people around them. This raises the possibility that some people may be more comfortable talking about death, and perhaps actually do talk about death more, than they report. All participants suggested that many other people were not comfortable with the subject of death, and most expressed the opinion that people in general do not talk enough about death. It seemed to be an important part of the identity of many respondents that they were able to talk about death and dying more freely than most. These findings also reflect the findings of other research [111, 120] in which respondents often reported being more comfortable than other people about talking about death. These findings suggest that people might often wrongly judge that

others might be uncomfortable talking about death, and might therefore avoid the subject unnecessarily.

The findings do not support the popular view that the UK is a 'death denying' society or that there is a general 'taboo' associated death, despite many participants talking of a taboo. Making certain preparations for death was considered normal, even a responsibility, supporting arguments against the denial of death [12, 77, 81]. Most participants reported having various conversations about death with people around them. One participant, who had previously hesitated to discuss end of life wishes with her mother and daughter, commented after having had those conversations that death was, 'not taboo'. However, death was not usually considered a suitable topic for a social occasion, unless approached in light-hearted way. Context seemed to be very important, as were various individual and inter-personal factors. Some people, for different reasons, appear to purposely avoid or limit their engagement in conversations about death, especially relating to their own death or that of somebody close to them. Reasons included fear, sadness, or a perceived need to concentrate on staying alive or well. These barriers have also been identified in other research [116, 125]. Others would like to talk about death, but worry about the reaction of or effect on other people; a finding also of other studies [117]. Most participants had experience of somebody either closing down a conversation about death or making it clear they did not want a conversation to start, mirroring earlier research with older adults [56]. Talking about death was sometimes described as 'morbid' or 'maudlin'.

In common with the questionnaire survey, the findings go against the common assumption that people might not talk about death because they feel uncomfortable with the subject. The words 'uncomfortable' or 'not comfortable' were rarely used by participants in this study. Where they were used, it usually related to talking to somebody who was dying about their plans, or talking to somebody who had been bereaved about their loss. This suggests concern for the other person's feelings or reactions, rather than their own discomfort with the subject. When it came to their own feelings about talking about death, descriptions of the personal barriers to discussions more often related to lack of experience, confidence or knowledge. As feeling 'comfortable' about doing something is quite a vague and complex construction, lack of confidence might be a factor which prevents people from feeling comfortable, might be a separate factor, or might be reported differently by different people.

### **9.1.2 Planning for and talking about end of life**

The findings appear to confirm the experience and intuition of palliative care professionals and policy-makers that considering and discussing end of life plans and preferences with close family or friends, while still well, is usually a good idea [18, 25]. Participants were also of this view, and provided many examples of situations where having had these conversations made coping with a death easier than it otherwise would have been, and other situations where not having the conversations caused unnecessary distress or conflict. There were two main motivations for expressing wishes while well: firstly and most importantly, it may be the only opportunity in case of sudden decline or death; secondly, it might provide a sort of 'practice', making future end of life discussions, when a person might be unwell and closer to death, easier.

The findings also seem to show that people are dying without making a will (or without telling anybody where the will is) or telling the people closest to them whether they want to be cremated or buried; sometimes causing unnecessary administrative and legal hassles, financial problems, family conflicts and emotional distress. A qualitative study such as this is not able to quantify the extent of these problems, but it does provide evidence that they exist.

The main motivations for discussing end of life preparations and preferences were usually to make things easier for family left behind, in common with the findings of other studies both in the UK and in Australian Aboriginal communities [8, 117, 123]. Perceived benefits included minimising disagreements among family members at times of dying and mourning; ensuring that assets and personal possessions went to the 'right' people; reducing workload and stress for the people arranging the funeral; helping family members to feel that they have 'done their best' for the person who had died; and helping people who were dying to get their own wishes met. These perceived benefits exactly mirrored the reported benefits or problems experienced in situations where a person had or had not prepared for their end of life and discussed their end of life preferences. This suggests a widespread awareness of the potential benefits of end of life planning and discussion. Participants also reported more immediate emotional benefits of having these conversations, including helping people to feel closer to one another and focusing on what was important to live well. These immediate benefits were expected by the CLWDW team, but, as far as the researcher is aware, have not been confirmed by previous research.

There appeared to be a general hierarchy of priorities to end of life planning and discussion, which varied slightly by age and according to individual circumstances. Making a will was generally the top priority, followed by expressing preference for cremation or burial, sometimes followed by expressing wishes regarding medical treatment and care in the event of sudden incapacity. For example, a person might write a will in case of their unexpected death, but not discuss their funeral wishes, because death seemed a long way off; another person might both write a will and plan their funeral, but not talk about their end of life care, because they were still well, and had no idea how or when they would die and therefore what care they might want. Younger participants also often valued discussions about organ donation, and older participants often wanted to arrange and pay for their own funeral. The level of detail to which participants wanted their plans to go into, and the amount of discussion they wanted, varied considerably. Often, plans for end of life were not viewed separately from other types of planning; but as part of planning for the future, or looking after the family. In the general, while well, preparations for the social aspects of dying were given much higher priority than those for the physical aspects. Most participants did not mention their own end of life treatment and care at all. It appeared to be both a low priority and, in common with earlier research findings, something which they expected to have limited control over in any case [124]. These priorities appear to contrast greatly with those of most research; which has tended to concentrate on advance care planning [133].

It appeared that when people were well, conversations about end of life preferences were often easy and natural, provided that the other person was willing to listen. Most respondents reported having had these conversations without any concern. Some worried or found it difficult to start the conversation, but once started, also found it easy. Others did not regard these conversations inherently difficult, but, as identified by other researchers, felt they did not have sufficient knowledge of the options or processes [127] or worried about upsetting the people closest to them [117]. Others had difficulties finding the right moment or suitable way to start the conversation, especially if they did not see their family very often [129].

However, there were circumstances where people found it difficult, impossible, or unhelpful to talk about their end of life preferences. These included situations where a person was focussed on staying alive, well, or 'positive', for example, during active treatment for a life-threatening illness, or were coming to terms with a life-limiting or terminal diagnosis. This supports the findings of earlier research in people with COPD [125]. There were also situations where the conversations were avoided

because they were upsetting to the person closest to them, and sometimes more than one of these factors was present. As described earlier, a minority of the population, as described by the participants, seem to find discussions about end of life preferences difficult or impossible at any time. Most commonly, they were thought to be afraid of death or bereavement, or to have previously suffered a traumatic bereavement.

Sometimes, in situations where discussion was too difficult, it was reported to be helpful for the person to write down information on their end of life preferences and preparations, and tell the people closest to them where to find the information. Family members were also sometimes, through tactful questioning, able to discuss the most important basics e.g. preference to be cremated or buried. In cases of terminal illness, people outside of the immediate family, such as nurses and faith leaders, could sometimes help to facilitate conversations, either by opening the conversation with the person who was ill, which might help them talk with their family later, or by direct involvement with the whole family.

Participants also identified circumstances where, for health or social reasons, it was difficult or impossible for people to discuss their end of life plans and preferences. In relation to health, they might have developed dementia, become very physically unwell, or suffered brain damage and become unable to communicate. Socially, they might be so isolated that they have nobody to talk to at all, especially if they are also disabled or unwell.

### **9.1.3 Supporting people who are bereaved, dying, or caring for somebody who is dying**

The findings seemed to confirm those of previous research [15, 73] that families affected by bereavement are often brought closer together, but sometimes find that old grievances and conflicts are reignited. Family members might support one another well, or might find that, because they grieve differently, and to different timescales, they are unable to support one another. People who had been bereaved therefore often needed the support of others around them who were less directly affected by the bereavement. Even when they did have the support of their close friends and family, it was important to them that others around them acknowledged their loss.

People who had been bereaved generally received support from their extended family, friends, colleagues and others in their community, and sometimes from people who they met after the death, who had often suffered a similar loss. However, as found in previous research, often old friends failed to get in touch, or people who they normally saw regularly avoided them [70], or avoided the subject of the death or deceased person [74]. There was a general understanding that when people acted in this way, it was usually because they did not know what to say, or were afraid of how the person would react. Despite this understanding, people still felt hurt if they were avoided or ignored, and felt burdened by others' discomfort if they avoided the subject.

Friends and family members who had been supportive close to the time of bereavement might not be supportive a few months later, when the person might still be grieving and might still benefit from their support. This was sometimes due to a lack of awareness of how long the process of grieving could take; or a belief that it was helpful to withdraw support and expect a person to 'move on'. It might also be due to their own need to 'move on', if they had also grieved for the deceased person; or because the bereaved person was difficult to be around, especially if they had been grieving for an extended period of time.

Participants who had experienced a close bereavement themselves, or who felt confident in supporting others who had been bereaved, described consistent views of appropriate supportive responses to people who had been bereaved. In summary, a bereaved person initially needed others to acknowledge their loss and let them know they were 'there for them'. They often appreciated practical help, for example, with arranging the funeral, or with everyday tasks such as cooking and ironing. At any stage of grieving, which may continue for months, years, or a lifetime, they might need to talk about their memories of the deceased person, and sometimes about how they felt and were coping with the bereavement. They might also, especially if they had lost a spouse or partner, appreciate additional companionship and support to maintain their social lives. These different supportive roles fulfil those described in previous research as practical support, social support and emotional support [67]. The accounts given of the support that people would like or have found that others have appreciated also very closely corresponds to the advice given in a leaflet available from Dying Matters, entitled, "What to do if someone you know has been bereaved", suggesting that this is common knowledge among people who work with people who are bereaved, if not with the majority of the population. With the exception of acknowledging the loss, they did not need all



of their friends to fulfil all of these rules; different people could fulfil different roles at different times.

While the majority of participants were confident in their ability to support others who had been bereaved, others were less so. Some stated that they 'wouldn't know what to say'. A few suggested that only a professional such as a nurse, faith leader or counsellor would have the skills to comfort somebody who was grieving. Despite this, all participants expressed a willingness to support others who were bereaved, however they could. It appeared that people who forced themselves to talk to somebody who had been bereaved, despite their worries, were usually able to provide some support and comfort to the bereaved person, or at least did better than ignoring them. People who had been bereaved sometimes said that nothing could have been said to make them feel better in any case, and others suggested that all that was needed was an acknowledgement of the loss and reassurance that people were 'there' for them. This suggests that there may be a common perception that providing comfort and support to somebody who has been bereaved requires more skill, knowledge and time than is actually the case. However, it is possible that the overall content of the interviews, which focussed on the role of talking, might have led some participants to disregard the role of brief supportive comments, practical or social support.

The definition of the state of 'dying' varied from person to person and situation to situation. It variously included being aware of 'getting old' or frail; being diagnosed with a terminal illness; being in a 'final illness'; or having only a few hours or days to live. People with dementia, or other life-limiting illnesses which progressed slowly, were not generally described as 'dying' until death seemed imminent, supporting the observation of previous author that they were not able to access the 'dying role' [42, 43]. This inconsistency in the definition of 'dying' meant there was insufficient data for a detailed analysis of views on supporting people who were dying or caring for people who were dying. However, some patterns did emerge. People with a life-limiting or terminal illness usually wanted to maintain their social contacts, and to spend time being 'normal' as well as having the opportunity to talk about their illness. They often also appreciated practical support to help them cope with their illness. However, in common with people who had been bereaved, they often found that people avoided them, or avoided talking about the situation, because they did not know what to say or were afraid of the reaction they would get. As in previous research, participants reported that people who knew they were close to death generally wanted to know that their affairs were in order, that their family was

prepared for their death, and that their life had been worthwhile [42, 43]. The people close to the dying person wanted to know that they had done their best for them [42, 43] and that they were 'at peace'. These ideals required a degree of open communication within families, in relation to emotional as well as practical matters, that, for various reasons, was not always possible when death was very close.

Carers and others who were close to persons who were dying also had different support needs depending on the situation. Long term carers might need practical support to be able to continue their own social life and interests. In a crisis situation, where death was very close, carers might need practical help or for somebody to be with them for emotional support around the actual time of death. Where they were already grieving, they might also need somebody to share their feelings with. Carers might also occasionally find that people avoided them, or avoided talking about the situation they were in, and they found this distressing and burdensome.

While some people who are dying, caring for somebody or bereaved find that their family, friends, neighbours and associates fail to adequately support them, others are isolated, and have no access to such a potential support network. Participants described how geographic mobility and busy lifestyles mean that many families and friends lived far apart and often people do not know many of their neighbours.

Poverty, disability and poor health could prevent people from participating in the wider community, especially if they have not previously been a member of a faith or community group. These people might have few others around them when they are dying or bereaved, and might benefit from the additional support of neighbours and volunteers, according to the Compassionate Communities model. This study identified some examples of members of the public taking the initiative to provide care and support for local people who were ill or bereaved, although they tended not to concentrate exclusively on end of life and bereavement, but on supporting anybody who was sick or in crisis. However, these informal systems tended to rely on the input of just one or two people, without which they would come to an end. Participants also identified barriers which very informal systems need to overcome. A social network needs to be established, which may be difficult in areas with high mobility or where few people have the opportunity to meet one another. The people offering support also need the courage to risk being rejected or considered 'nosey', and the people needing support might sometimes not wish to accept it, as they might fear being seen as less self-sufficient.

#### **9.1.4 Participants' views on the role of public health activities**

Most participants were optimistic that it was possible to make a difference to how people prepare for their end of life and discuss their end of life preparations and preferences. This optimism was based both on the success of other public health campaigns, such as tobacco control, and the current openness about issues such as cancer which, in the past, were talked about far less openly. There was also a common perception that people were already becoming more open about death and the media more active in discussing issues relating to death.

Participants put forward various suggestions for activities to speed up this progress. They suggested educating the public about death and preparations for death; improving access to relevant information; promoting discussion and dialogue to help to normalise death, dying and bereavement; and supporting people who need help to plan for the end of their life or to discuss their preparations and preferences with the people close to them. The most common activity themes were educating children, providing information about end of life planning to adults, and raising awareness among the general population in order to stimulate conversation about death and dying.

There was no similar consensus on what, if any, activities might improve the way people support others around them who were dying, caring, or bereaved. Some participants suggested making information available on how to support somebody who was dying or had been bereaved, for example via a web-site. Others suggested encouraging general discussion of how best to support people in these situations through education of children and young people and items in the media. It was also suggested that activities to normalise death and bereavement and encourage more openness about death in general might help. However, around half of the participants believed that many people did not have the time, interest, empathy or natural ability to talk with friends or associates to support them in their bereavement, and that no public health interventions could make any difference to that.

### **9.2 Strengths and weaknesses of the study**

This study investigated an area which has been little researched before, and is generally considered to be a sensitive subject. Consequently there were some concerns that it would be difficult to recruit enough participants or that participants would not have much to say. In fact there were no problems in recruiting enough

participants and they all seemed eager to share their views and experiences. This was also the experience of the few other qualitative researchers who have investigated this area, and who have been able to collect data and write papers on people's views about death and dying [49, 56, 60, 125, 188] sometimes without directly asking about it [49] and, in one study, as an unexpected outcome of a study on a different topic [60]. It also reflects the findings of a survey conducted in Canada, where only nine percent of respondents agreed that end of life is too sensitive a topic to talk about [118, 119].

Partly because of these concerns, the study sampling strategy was one of convenience, including at first all persons who were interested enough in the study to respond to a participation invitation sent by postal letter and email. In hindsight, it would probably have been possible to employ a more purposive sampling strategy, as the level of interest was higher than anticipated. However, the recruitment process, with its onus on the potential participant to contact the researcher, meant that the sample would always be highly self-selected, whatever sampling strategy was used.

This high level of self-selection may have contributed to the richness of the data collected, as it meant that many of the participants had a particular interest in the research subject, and were therefore motivated to share their experiences and ideas. Almost a third of participants were members of staff or volunteers in palliative care or public health end of life services and projects. The sample also over-represented, compared to the UK population, people who were actively involved in church work, informal carers and people who worked in the field of social care. Many of the participants therefore had had more contact than average with people who were dying or bereaved, and were able to share knowledge they had gained from that experience.

As the sample did not, in terms of type of activities they were involved in, accurately reflect the characteristics of either the local population or the participants in the quantitative research strand, it is possible that their views and experiences were systematically different in some unknown way. There is no evidence that this was the case; participants who were involved in palliative care or public health end of life work did not report systematically different views from participants with other backgrounds, although often they used different language to express similar views.

Another difference between the study sample and the general population was that the majority were employed in, or were retired from, professional jobs, and lived in relatively affluent areas. This was partly because the study area is relatively affluent compared to the UK in general and partly due to the self-selection of the participants. There was therefore very little first-hand data collected about what it is like to prepare for death or to be bereaved while facing social and economic deprivation. Only one participant expressed concern on his own account over the cost of a will and funeral. These issues might have a greater effect on people with less money to spare. Levels of education may also affect views and experiences. Further research, including more participants of a lower socio-economic status or living in deprived areas, would be useful to investigate these differences.

Qualitative social research is usually undertaken with people who are all in a particular situation, or of a particular group in society. This study was slightly unusual, as the area under investigation is something which affects the whole population. The researcher, and her advisors, were also of this population, and had their own experiences and ideas on the subject. It was therefore more difficult than usual to take the questioning viewpoint of a 'stranger' to the community under investigation [191]. The background of the researcher might therefore have had more influence in the collection, analysis and interpretation of data than might have been the case if the subject was one which affected on a specific group. The researcher had no personal experience of life-threatening illness, close bereavement or caring for someone who was dying. A researcher with personal experience of these phenomena might have had a different perspective, and hence reported slightly different findings. The researcher's professional background was in applied public health research, and as a result her natural inclination was to approach the research with a view to its practical applications. A researcher with a different background might have had a different perspective, and hence again reported slightly different findings, or placed emphasis on different aspects of the findings.

Despite these uncertainties, there is evidence that the findings are credible and confirmable, i.e. that participants would recognise the account given, and other researchers would have reported similar findings. Ideally, the credibility of a study would be enhanced by asking participants to review summaries of what they had reported to the researcher, or to review the study findings, to check that the accounts agreed with the account that they had intended to convey [192]. Participants were given the opportunity to read transcripts of their interviews but

most did not take up this offer and none made any comment. There was not time to ask all participants to review the entirety of the findings before writing up. It might, however, have been possible for participants to have reviewed themes as they emerged following their own interview. Participants might have welcomed this opportunity, but equally might have considered it a burden, or refused to get involved. It would also have been time-consuming, making it difficult to include within a mixed-methods study. However, participants will be able to comment on the findings at a later stage. Following publication of the thesis, they will be sent a plain language summary of the findings, invited to request copies of the full thesis if they wish, invited to comment on either. Any comments received will be taken into account in any future publications of this research.

For the purposes of the thesis, input from the participants is probably not essential for the trustworthiness of the findings. The knowledge area covered by the study is one that affects the entire population, including the researcher, her supervisors and external advisor, who all recognised the account as credible. Confirmability would have been enhanced by having another researcher also working on the analysis. However, this was not appropriate for a PhD thesis. Another sign of the trustworthiness of the study is that, where subject areas overlapped with those of other research, their findings tended to agree, as illustrated throughout the discussion section.

The interview topic guide covered a wide range of potential topics relating to talking about death, dying and bereavement, because, in a subject area where so little previous research had been conducted, it was important to keep the questions wide to identify areas of importance to the participants. However, this meant that, for some of the themes included in the analysis, there was limited data. The core subject areas, for which more comprehensive data were collected, were preparations for end of life; talking about death, dying and bereavement in general; and supporting people who have been bereaved. There was less data about the views and experiences of people who were dying and their carers.

### **9.3 How the qualitative and quantitative research strands complement one another**

In many ways, the findings of the qualitative study confirmed the findings of the quantitative. The majority of respondents of and participants in both research

strands reported feeling comfortable with the idea of talking about their own and others' end of life wishes or comforting people who had been bereaved. Participants in the qualitative study described talking easily about these subjects with friends, family and acquaintances. A small proportion of questionnaire respondents and some acquaintances of qualitative interview participants did seem to be uncomfortable talking about death. A larger proportion, however, seemed to lack confidence, usually described as 'not knowing where to start' with conversations about end of life wishes, or 'not knowing what to say' to people who were bereaved or dying. This lack of confidence seemed to be related to both a lack of knowledge and information, and lack of experience of these conversations.

In both research strands, participants talked of a 'taboo' around death and dying. However, in the qualitative interviews, it was apparent that participants' descriptions of this 'taboo' actually referred to a more complex set of barriers. It was not usually appropriate, for example, to talk about death while attending a social event, or when other people did not want to join that conversation. However, this was not always the case, as general conversation about death could sometimes be light and humorous. It might be more difficult, and sometimes inappropriate, where people were being treated for life-threatening illness, or coming to terms with a recent terminal diagnosis. There also seemed to be a common perception that, while a person might themselves feel comfortable talking about death, other people generally felt less comfortable. Participants who had overcome this barrier described mainly positive responses, suggesting that this perception is often wrong. Another frequent barrier is the feeling of fear or distress that some people experience when thinking and talking about their death or the death of someone close to them. Although this phenomenon would not generally be described as a 'taboo', it was described as such by some of the participants.

The qualitative interviews mainly confirmed the quantitative survey findings of a general lack of interest, among people are well, in planning for end of life care. A few participants expressed a vague interest in something similar to a living will or advance directive, but did not know how to go about it, and did not believe that health professionals would respect their wishes in any case.

The qualitative study also seemed to confirm that CLWDW public health events were well received, successful in encouraging attendees to discuss their end of life wishes with the people closest to them, and that many attendees talked others about the content and messages of the events, thereby helping to increase the

reach of the intervention. It also gave some further insight into why the events were so successful.

The style and delivery of the events seemed to be a factor in successfully engaging the attendees. Participants praised the format, delivery, and the public health worker herself as 'positive', 'sensitive' and 'with humour'. Without this engagement, participants may not have related so strongly to the content and message. The actual mechanisms by which the intervention worked to increase discussion about end of life plans and preferences appeared to be multiple, and corresponded to the main factors in theories of behaviour change: decisional balance [172] and self-efficacy [176].

Many participants described the events as 'not as morbid' as expected, 'more positive' than expected, or 'more humorous' than they expected. They described talking with people who had attended the event with them and who had made similar comments. This suggests that the events might have played a role in changing views and perceptions of talking about death in a positive way. It could be the case that, as described in the Theory of Planned Behaviour [169, 170] the events might change subjective attitudes towards talking about death as something that is a positive thing to do. Participants in the qualitative study often described themselves as unusually open about the subject, and seemed to view this as an important part of their identity and self-image. In attending the events with others, and talking with others about the events, and seeing their positive reactions, perceptions of normative social pressure might also change in a positive direction. One participant expressed this experience as 'realising that talking about death is not taboo'. This potential change of perception regarding the social acceptability of talking about death is referred to in the Transtheoretical Model as 'social liberation'.

Participants in both research strands described CLWDW events 'prompting' them to take action. The word 'prompt' perhaps suggests that it was already something they were considering, and they were therefore already at the contemplation and preparation stages of the Transtheoretical model [171-175]. This is supported by other findings. All the interview participants seemed to have been intuitively aware, before attending the events, of the benefits of having certain preparations in place before death; and of telling the people closest to them about their preparations and preferences. In the quantitative survey, the majority of participants who did not have a will reported that they were considering making a will. The idea of a 'prompt' seems to approximate to the concept of consciousness-raising in the



Transtheoretical Model. If a large proportion of the study population were already contemplating taking some action, and thus had fewer stages of change to go through before taking action compared with those who had not thought about it, this might also go towards explaining the high rates of reported actions taken over the three-month follow-up period.

A few participants talked of themselves or others 'realising' after attending an event that they needed to prepare better for the end of their life. This suggests that they might not have previously considered these preparations, or might have considered them but not seen them as so important. According to the Transtheoretical model, they were at the pre-contemplation or contemplation stage, where the effect of the intervention in both consciousness-raising (raising awareness of the benefits), and of environmental realisation (increasing awareness the potential effects on other people of not having a will or information on funeral wishes), might positively influence the decision to take action.

Participants in both research strands also talked of having increased confidence to start conversations about end of life wishes. Respondents and participants who attended the 'How to' workshops reported this more often than those who attended the 'Awareness-raising' events, reflecting the aims of the workshops. This increased confidence directly relates to the concept of 'self-efficacy'. In the Transtheoretical model this becomes relevant at the contemplation and preparation stages. In the Theory of Planned Behaviour [169, 170] this is one aspect of perceived behavioural control, which is one of the three major factors on which a decision to take action depends.

The Transtheoretical model, in particular, might help explain the success of the CLWDW events. The model postulates that, before making a significant change, a person who has not yet contemplated the change needs to move through two intermediate stages; contemplation and preparation. Different inputs can influence a person's journey through these different stages. For example, movement from pre-contemplation to contemplation might be facilitated by hearing information on the benefits of change; movement through contemplation might be facilitated by increased self-efficacy (confidence that they can make the change) or realisation that the change is socially acceptable; and movement through preparation to change might be facilitated by the opportunity to discuss it with others. By providing information and ideas within a supportive group situation, and including time for discussion, the events could potentially influence journeys through all stages. The

high success rate in prompting discussion of end of life preferences by three months' follow-up might be also explained by the high proportion of the target population who were already both aware of the potential benefits and comfortable talking about death; i.e. were at the contemplation or preparation stages. This suggests that the ideas and opportunities for discussion may have had more influence than the actual information given. It also suggests that the benefits of the events might continue past the three-month follow-up point, as some attendees who had not yet taken action continue to move through the stages towards change.

However, change of behaviour theories are not the only models which might be applied to similar intervention. For example, the design of the CLWDW events was consciously underpinned by educational theories and good practice, including catering for different learning styles and emphasising participation rather than passive receipt of information. An intervention which did not take account of these learning theories, and was consequently less varied or engaging, might be less successful in its aims.

## **10. Conclusions**

### **10.1 Summary of findings**

This thesis has demonstrated the feasibility and acceptability of undertaking research with the general public about their needs and attitudes relating to preparing for and talking about death and dying. The researcher, in common with others who have conducted research in this area, found that people of all ages, and from many different backgrounds, were willing to complete a questionnaire or talk about the subject, and were not distressed by this.

It has also confirmed that the social and emotional aspects of dying and bereavement, and the need to prepare for and talk about it, are in many ways universal. There were few major differences identified between males and females, young and old, and people living in affluent or deprived areas. There large similarities between the findings of this and other research, including research conducted within different countries and cultures.

Common wishes associated with dying include ensuring that one's own death causes as little distress as possible to others; that possessions are distributed as one wishes, to 'do one's best' for and respect the wishes of loved ones who are dying or have died; and for self and others to die without pain and 'at peace'.

People who have been bereaved want others to acknowledge their loss, want to talk about their memories of the person who has died, and often also want practical, social and emotional support from those around them. People generally want to be supportive to those around them who are dying, caring for somebody who is dying, or bereaved, but do not always know how to offer and provide this support.

However, as might be expected, certain needs and interests vary with age and circumstance. For example, an older person might want to plan and pay for their own funeral, whereas a younger person, unless they had a life-limiting illness, might just want to let somebody know whether they want to be cremated or buried when they die. A person with little disposal income might hesitate to make a will, seeing it as expensive, while a person with more resources might experience fewer barriers to making a will and see it as a higher priority.

There appears to be widespread awareness of the potential benefits of making a will, telling people about the will, and letting people know funeral and end of life care preferences. Many people have had positive and negative experiences, or have heard stories of others' experiences, which confirm this knowledge. Generally, among people who are currently well, writing a will is given the highest priority, following by planning or discussing a funeral. Planning for end of life care appears to be a very low priority among most people who are well. This contrasts with the priorities of the majority of researchers and health policy makers, who have most often focussed on end of life care planning or advance directives. The welfare of family and friends after one's death is generally given higher priority than one's own wishes.

Despite this knowledge, experiences of the interview participants suggest people are still dying without having made a will or letting people know their funeral wishes, and this is causing unnecessary stress and distress to those left behind. This does not seem to be caused by widespread discomfort, or a taboo, surrounding conversations about death. Most people seem to be fairly comfortable with the subject, in the right situations. It is often (but not always) considered too 'morbid' a topic for everyday social conversation, and might be difficult for people who are trying to 'stay positive' when undergoing treatment for life threatening illness, managing a chronic illness or coping with a recent diagnosis. However, as a subject of conversation between people who are well and close to one another, the concept of a taboo does not seem to explain the lack of discussion.

Instead, lack of planning and discussion seem to be related to more specific factors, which perhaps might more easily be targeted and overcome. The most commonly reported barriers, in this research and others, include feeling that death is too far away, 'not getting round to it', not being able to find the right time, not knowing how to start a conversation, not wanting to upset others, finding that other people do not want to discuss it, and not having sufficient knowledge of the options. There also appears to be a minority of people who experience barriers which might be more difficult to overcome. Some appear not to be interested in what happens after their death. Others find it difficult to contemplate their own death, due to extreme fear of growing old, the dying process or of death itself. A few are so isolated they have nobody to talk to about end of life preferences, or anything else.

Although there is widespread awareness of the benefits of preparing for end of life and discussing end of life preferences, in other areas there appears to be widespread 'death ignorance'. This includes ignorance of what happens to a person around the time of and after death. This contributes to fear of dying, which many described as 'fear of the unknown', and fear of being unable to cope with life-limiting illness or bereavement. Many know little about the usual course of grief following a close bereavement, which can be a long process with many ups and downs. This may be causing unnecessary suffering for people who are bereaved, as they wonder whether they are 'normal'. It might also prevent people from effectively supporting family members, friends, neighbours, colleagues and others in their social network who have been bereaved, because they do not know what to say or how to help. People who are dying, or are caring for somebody who is dying, can also experience similar problems to those who are bereaved, as people around them do not always know how to respond.

People who are bereaved often find that the most effective emotional support comes from people who have suffered a similar bereavement experience. Systems which bring people with similar experience together, such as support groups or on-line forums, can therefore be a great support.

People who are bereaved or dying might also not have people around them who could support them, even if they knew how. Many people know few of their immediate neighbours. Family, friends and colleagues may be supportive, but may live too far away or be too busy to provide immediate practical or on-going support. People who become ill at the end of their life are most often elderly, and may have already become isolated due to ill health and bereavement. People who die with

generative diseases such as dementia may have become isolated in the course of their illness. When people lose a spouse or partner through bereavement, especially if they are in poor health themselves, they might suffer from isolation in addition to their grief. These people might benefit from the support of other members of their community, who are not part of their established social network, whether they are volunteers in a formal scheme or concerned individuals.

## **10.2 Implications for public health policy and practices**

The findings argue against the idea that there is a taboo around death, which, if broken, would allow people to talk more openly about their end of life wishes and to better support others who are dying or bereaved. Instead there seem to be various specific barriers, which might suggest specific interventions. However, non-specific interventions, intended to raise the topic of dying and bereavement and to open general discussion on the subject, might still be beneficial. Examples might include educating children about the death traditions of different religious faiths, or putting stories, debates and factual articles on radio and television. By increasing the amount of general discussion in both the media and population, public perceptions of the acceptability of talking about death might improve, awareness of the issues might increase, and the confidence that people have in their ability to have these conversations might also increase. These positive background changes might both directly facilitate open discussion about death and bereavement and provide a more receptive background for more specific interventions. These activities can also sometimes provide individuals with 'prompts' which might remind them of a conversation they intended to have, or provide them with an opening for a conversation they want to have.

There also appears to be a role for public education about death and bereavement, and for the provision of information that is easy to access, which might also be organised at both a national and a local level. People are often unsure of what happens to a person when they die, or what the procedures are for registering a death and organising a funeral. This can contribute to fear of dying, or fear of not coping with bereavement. Many are also unsure of what the process of grieving is like, and how best to support people around them who have been bereaved. Public education in this area might reassure some that their grieving is 'normal', and give people the knowledge and confidence to support others who have been bereaved. It

might be helpful to people facing these situations if there was a well-known and easily accessible source of relevant information. Most people seem to be already aware of the benefits of writing wills and telling people their funeral wishes, although some are unsure where to start with the practicalities of arranging these things.

These public education and information-providing functions might be delivered by combination of national and local organisations. Specific resources might be developed at a national level. The Dying Matters website and leaflets, which include information on grieving, supporting people who have been bereaved, and preparations such as wills and funerals, might perhaps be more widely publicised and distributed than at present. Further information and educational resources might be developed, especially on the physical aspects of ageing and dying and the care available. Central guidance might be provided for schools. Locally, organisations or partnerships might work with or advise schools and youth organisations; distribute information leaflets; raise awareness of the work of hospices and other organisations caring for people who are dying or bereaved; and put on arts events, drama projects, local radio shows and various other activities.

More specific interventions are probably better facilitated at a local level. A holistic public health approach, such as that taken by CLWDW, has the potential to address the three main problems identified in this thesis; people being unprepared for death due to lack of planning and discussion; people not knowing how best to respond to others' illnesses and bereavements; and people becoming isolated by illness and bereavement, especially near the end of their life. The partnership approach developed by CLWDW is a good model for other areas wishing to improve end of life experience. This approach helped to standardise and publicise the public health messages and enabled a range of complementary activities to be undertaken and resources to be developed. However, where such a comprehensive partnership is not established, there is still scope for individual voluntary projects and smaller partnerships to make a difference.

Most people appear to be already aware of, or can easily become aware of, the benefits of making certain preparations for death, and, in the right circumstances, most feel comfortable talking about these subjects. However, many have not done these things because they think that death is too far away, have not got round to it, do not feel they know enough about the options available, or are unsure how to start a conversation on the subject. This provides the conditions where low-intensity interventions such as the CLWDW events, designed mainly to raise awareness and

improve availability of relevant information, can be effective in encouraging end of life preparations and discussion. Similar events, perhaps modified to local conditions, might therefore share similar success.

The success of the CLWDW events could also be attributed to their high quality. To maintain interest, a range of topics were covered in range of different delivery formats to suit different learning styles, and attendees also appreciated the sensitive facilitation, humour, and opportunities for discussion provided by the events.

The CLWDW presentations and workshops were pre-prepared, adapted slightly to the needs of different groups. This was done partly to efficiently deliver a new message to as many people as possible, and partly to aid interpretation of the research results. As CLWDW continues, events are being more individually tailored to their audiences. Other delivery models might also be considered; for example, activities might be planned in partnerships with community groups, in accordance with the expressed needs and wants. Events might also be of the 'drop-in' variety, for example as a stand-alone event in a public space or a stand at public event. Drop-in events, as identified in the systematic literature review [133] can encourage people to engage, there and then, in discussions about their end of life wishes, and might provide opportunity for brief discussion or provision of information to people who would not attend an hour-long presentation. The range of topics covered in such events might perhaps be enlarged or amended to include awareness-raising about bereavement. Alternatively a separate awareness-raising programme might concentrate on bereavement.

One challenge in delivering awareness-raising events is getting people to attend. The majority of CLWDW Awareness-raising events were delivered at regular community group meetings, within a 'visiting speakers' space. Attendees were therefore generally aware in advance of the subject of the presentation, but had often not made a particular effort to attend. This worked well, although some groups observed that attendance on that occasion was lower than usual, as some people had avoided the events. For some people, in some circumstances, choosing not attend might have been in their best interest; for example, if they had suffered a recent bereavement; were focussed on positively managing a chronic or life-threatening illness; were coming to terms with a terminal diagnosis or had an extreme fear of death. Some who had attended the events commented that they enjoyed it more than expected. More targeted advertising, focussing on what is most important to most people, for example, "looking after loved ones after your

death”, might have the potential to increase attendance rates. Events specifically provided for health and social care professionals also attracted significant numbers, perhaps attracted by the opportunity for professional development. CLWDW events that were openly advertised for the public attracted few people; ‘roadshow’ or ‘drop-in’ type events, where people feel free to come and go as they like, might have attracted larger numbers.

General ‘aware-raising’ type events might be effectively complemented by more targeted interventions, which people might actively choose to attend, depending on their interests. The CLWDW ‘How to’ workshops, designed to increase skills and confidence in starting conversations about end of life wishes, were positively rated and appeared to be effective in facilitating conversations. The systematic literature review identified that workshops for older people, providing information and opportunities to discuss the process of end of life planning, were appreciated by those attending [137, 189, 190]. Similar workshops were suggested by some older interview participants as something which they or others might be interested in. Information events about wills might be of interest to all age groups, especially if connected with the opportunity to receive individual advice either free of charge, or at an affordable, up-front cost. This might perhaps be linked to charity fund-raising such as the annual ‘wills week’ run by participating solicitors or information events already run by various charities. Needs may be different for affluent versus deprived areas, or for individuals with high or low incomes.

The priorities of people who are well are usually related primarily to the welfare of their family after or in the event of their death. On a practical level this relates primarily to making wills and either planning a funeral or letting family know about funeral wishes. People are also receptive to ideas such as bucket lists and emotional wills, which might help people to prepare emotionally for death while also concentrating on living well. Few people seem interested in planning for end of life care while still well, when they have no idea how or when they might die. The current policy of concentrating end of life care planning resources of people thought to be in their last year of life therefore seems very appropriate. It might, however, be useful to raise awareness of the options for choice and recording preferences, such as Preferred Priorities of Care documents and Advance Directives, as there is currently a perception that there would be no choice in end of life treatment and care.



Support for people who are bereaved might perhaps be improved by increasing public knowledge of bereavement, grief and how best to respond to and support people who are bereaved. However, often the best people to support those who have been bereaved are other people who have had a similar experience. Some people find bereavement support groups, and perhaps internet-based bereavement forums, a comfort and support. Various bereavement groups are provided already by voluntary organisations such as hospices and churches. It is important that support for these groups is continued, as they might sometimes require funding to continue, for example, for room hire or telephones.

Everyday support for people who have a life-limiting or terminal illness, or are caring for somebody with such an illness, might also be improved by increasing public awareness of how best to respond. However, in situations where people are isolated or in crisis, a more intensive and organised form of support might be beneficial. It is important that this support is voluntary and separate from clinical and formal social care services. Giving compassion in palliative care has been defined as developing trust within a continuous process of engagement and meaning making; while experiencing compassion has been described as being treated as a person, rather than a disease process [193]. Staff in formal services may be motivated by compassion but time constraints and organisational pressures can make this difficult. Volunteers are less susceptible to these pressures and are free to concentrate wholly on providing compassion and support.

Already there are various local voluntary schemes, networks (such as church groups), and some very informal systems set up by individuals or small groups within their local neighbourhoods, to support people in these situations. These probably cover only a minority of the population and, where there is little or no formal infrastructure behind them, often rely heavily on one or two people, and are therefore precarious. If this type of volunteer support is to be extended significantly, some degree of formality, and some funding support, would probably be required. A funded service could provide a stable structure; training and support for volunteers, visibility as a resource for the community; and legitimacy, facilitating volunteers' access to people's homes. When deciding the remit of such schemes, it will be important to take into account that isolation due to illness and bereavement does not only affect those who have a diagnosed terminal illness or are believed to be in their last year of life; people might live many years with chronic illness and disability.

### **10.3 Areas for further research**

The fieldwork for this thesis was undertaken with a relatively affluent population; more research is needed on the specific views and needs of people with limited resources or living in deprived areas. For example, those with few possessions and little money probably have different views and needs around wills, and may not have access to formal procedures such as power of attorney.

Participants in the interview study suggested that volunteers might have a role in supporting people with a life-threatening or terminal illness who need support to talk with their families about their end of life wishes. This was not a main area of research within this thesis, but might be suggested as an area where further research is needed.

Although many participants suggested that providing education and information about how best to support people who have been bereaved might improve the availability of support from the people around them, around half were doubtful, suggesting that being supportive depends on empathy, which cannot be taught. This suggests a role for further research into how people give and receive support relating to dying and bereavement.

Health promotion and 'Compassionate Communities' type projects relating to death, dying and bereavement are a recent innovation and hence little research has been done into their implementation and effectiveness. Further research in these areas would therefore be useful. Small-scale projects which do not have a research budget might be encouraged to undertake as detailed an evaluation as they are able, and to publish the results, as this would also provide valuable information for others planning similar activities.

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## Appendix 1: Quality Assessment Criteria for Systematic Literature Review

<p><b>1. Abstract and title: Did they provide a clear description of the study?</b></p> <p><b>Good:</b> Structured abstract with full information and clear title.  <b>Fair:</b> Abstract with most of the information.  <b>Poor:</b> Inadequate abstract.  <b>Very Poor:</b> No abstract.</p>
<p><b>2. Introduction and aims: Was there a good background and clear statement of the aims of the research?</b></p> <p><b>Good:</b> Full but concise background to discussion/study containing up-to date literature review and highlighting gaps in knowledge.  Clear statement of aim AND objectives including research questions.  <b>Fair:</b> Some background and literature review. Research questions outlined.  <b>Poor:</b> Some background but no aim/objectives/questions, OR Aims/objectives but inadequate background.  <b>Very Poor:</b> No mention of aims/objectives. No background or literature review.</p>
<p><b>3. Method and data: Is the method appropriate and clearly explained?</b></p> <p><b>Good:</b> Method is appropriate and described clearly (e.g., questionnaires included).  Clear details of the data collection and recording.  <b>Fair:</b> Method appropriate, description could be better.  Data described.  <b>Poor:</b> Questionable whether method is appropriate.  Method described inadequately.  Little description of data.  <b>Very Poor:</b> No mention of method, AND/OR Method inappropriate, AND/OR No details of data.</p>
<p><b>4. Sampling: Was the sampling strategy appropriate to address the aims?</b></p> <p><b>Good:</b> Details (age/gender/race/context) of who was studied and how they were recruited.  Why this group was targeted.  The sample size was justified for the study.  Response rates shown and explained.  <b>Fair:</b> Sample size justified.  Most information given, but some missing.  <b>Poor:</b> Sampling mentioned but few descriptive details.  <b>Very Poor:</b> No details of sample.</p>
<p><b>5. Data analysis: Was the description of the data analysis sufficiently rigorous?</b></p> <p><b>Good:</b> Clear description of how analysis was done.  Qualitative studies: Description of how themes derived/ respondent validation or triangulation.  Quantitative studies: Reasons for tests selected hypothesis driven/ numbers add up/statistical significance discussed.  <b>Fair:</b> Descriptive discussion of analysis.  <b>Poor:</b> Minimal details about analysis.  <b>Very Poor:</b> No discussion of analysis.</p>

**6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained?**

**Has the relationship between researchers and participants been adequately considered?**

**Good Ethics:** Where necessary issues of confidentiality, sensitivity, and consent were addressed.

**Good Bias:** Researcher was reflexive and/or aware of own bias.

**Fair:** These issues were acknowledged.

**Poor:** Brief mention of issues.

**Very Poor:** No mention of issues.

**7. Results: Is there a clear statement of the findings?**

**Good:** Findings explicit, easy to understand, and in logical progression.

Tables, if present, are explained in text.

Results relate directly to aims.

Sufficient data are presented to support findings.

**Fair:** Findings mentioned but more explanation could be given.

Data presented relate directly to results.

**Poor:** Findings presented haphazardly, not explained, and do not progress logically from results.

**Very Poor:** Findings not mentioned or do not relate to aims.

**8. Transferability or generalizability: Are the findings of this study transferable (generalizable) to a wider population?**

**Good:** Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).

**Fair:** Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.

**Poor:** Minimal description of context/setting.

**Very Poor:** No description of context/setting.

**9. Implications and usefulness: How important are these findings to policy and practice?**

**Good:** Contributes something new and/or different in terms of understanding/insight or perspective. Suggests ideas for further research.

Suggests implications for policy and/or practice.

**Fair:** Two of the above (state what

**Poor:** Only one of the above.

**Very Poor:** None of the above.

## **Research Questionnaire**

### **Talking about Death, Dying and loss**

We would be very grateful if you could take a few minutes to complete this short questionnaire to help us gain a better understanding of this very important subject area.

Your answers will be used as part of a research project conducted by the University of Liverpool about how people talk to those close to them about issues relating to dying, death and bereavement. The project is supported and funded by Cheshire Living Well Dying Well Public Health Programme which is working locally to help raise awareness of the benefits of openly discussing these issues. Your answers could guide us in developing ways to help make sometimes difficult conversations easier and more comfortable for people.

The completed questionnaires will be kept securely at the University of Liverpool and any information you give will be kept confidential.

We would like you to include your contact details as we are interested to keep in touch and possibly ask you to complete a further questionnaire. However, you do not have to give us your contact details if you do not want to.

**Miss Katharine Abba**  
**PhD student**

**Prof Mari Lloyd-Williams**  
**Supervisor**

# Part 1

Type of Event:

Date:

## A. ABOUT YOU

### 1. Are you male or female? (tick one)

☐ Male    ☐ Female

### 2. How old are you? (tick one)

☐ Under 25                      ☐ 25 to 34                      ☐ 35 to 44                      ☐ 45 to 54  
☐ 55 to 64                      ☐ 65 to 74                      ☐ 75 to 84                      ☐ 85+

### 3. Who do you live with? (tick as many as apply)

☐ Husband, wife or partner                      ☐ Other family  
☐ Friends                      ☐ I live alone  
☐ Other (please state).....

### 4. What do you do? (tick any that apply)

☐ Work full-time                      ☐ Full-time carer  
☐ Work part-time                      ☐ Full-time home-maker  
☐ Not working due to sickness or disability                      ☐ Retired  
☐ Unemployed                      ☐ Other (please state).....

5. What town or village do you live in? .....

6. What is your postcode?\* .....

*\*We will use your postcode to see what type of area you live in, for example, town or countryside.*



**7. Are you considering making a will?**

- ☐ Yes                      ☐ No                      ☐ I have already made a will
- ☐ I already have a will but am thinking of making changes to it

**B. TALKING ABOUT YOUR WISHES**

**8. Have you ever talked with close family or friends about your wishes about your care if you became unwell and at the end of your life?**

- ☐ Yes
- ☐ No

**9. How comfortable would you feel about talking with a close family member or friend about your wishes about your care if you became unwell and at the end of your life, if you wanted to talk about it?**

(circle one answer on a scale of 1 to 10)

1= Not at all comfortable  
comfortable

10= Completely

1            2            3            4            5            6            7            8            9            10

**10. Have you ever talked with close family or friends about your wishes about what you would like to happen after your death?**

- ☐ Yes
- ☐ No

**11. How comfortable would you feel about talking with a close family member or friend about your wishes about what you would like to happen after your death, if you wanted to talk about it?**

(circle one answer on a scale of 1 to 10)

1= Not at all comfortable  
comfortable

10= Completely

1            2            3            4            5            6            7            8            9            10

### C. TALKING ABOUT OTHER PEOPLE'S WISHES

**12. Have you ever talked with close family or friends about their wishes about their care if they became unwell and at the end of their life?**

☐ Yes

☐ No

**13. How comfortable would you feel about talking with a close family member or friend about their wishes about their care if they become unwell and at the end of their life, if they wanted to talk about it?**

(circle one answer on a scale of 1 to 10)

1= Not at all comfortable  
comfortable

10= Completely

1      2      3      4      5      6      7      8      9      10

**14. Have you ever talked with close family or friends about their wishes about what they would like to happen after their death?**

☐ Yes

☐ No

**15. How comfortable would you feel about talking with a close family member or friend about their wishes about what they would like to happen after their death, if they wanted to talk about it?**

(circle one answer on a scale of 1 to 10)

1= Not at all comfortable  
comfortable

10= Completely

1      2      3      4      5      6      7      8      9      10

#### **D. TALKING ABOUT *BEREAVEMENT***

**16. Have you ever needed to comfort or support a friend or family member who has recently experienced the death of somebody close to them or is caring for somebody who is dying?**

☐ Yes

☐ No

**17. How comfortable would you feel having a conversation with a family member or friend about the death of somebody close to them, if they wanted to talk about it?**

(circle one answer on a scale of 1 to 10)

1= Not at all comfortable  
comfortable

10=Completely

1      2      3      4      5      6      7      8      9      10

---

**Thank you very much for your help**

**We have a few more questions that we would like to ask you, but not until after the session.**

**Please keep this questionnaire with you until then.**

---

## Part 2

**1. How relevant was the presentation to you and your life?** (circle one answer on a scale of 1 to 5)

1= Not at all relevant

5= Extremely relevant

1                      2                      3                      4                      5

**2. Was anything at the presentation particularly relevant, useful or thought-provoking for you?**

☐ Yes

☐ No

If 'yes' what was it?

**5. Are you planning to have any specific conversations with family or friends because of anything you have heard today?**

☐ Yes

☐ No

If 'yes' could you describe?

**4. Are you now considering making a will?**

- ☐ Yes                      ☐ No                      ☐ I have already made a will
- ☐ I already have a will but am thinking of making changes to it

**3. Did the presentation inspire you to do anything else or make any other changes in your life?**

- ☐ Yes
- ☐ No

If 'yes' what were they?

## Permission to contact you for further research

This questionnaire survey is part of a larger research project.

We would like as many people as possible to complete a similar questionnaire in about three months' time to help us to determine whether work that is being done by the Cheshire Living Well Dying Well Partnership makes any difference to people.

We are also looking for about 30 people to talk to us in more depth about their views about the importance (or not) of talking about end of life, death and bereavement, and what they think might help people to have these conversations if they want to.

We would like your permission for us to contact you about either of these additional research activities. We will give you more information about this research at the time, and you will be free to choose whether or not to participate.

**I give my permission for a researcher to contact me about me about further research in people's views and experiences of talking about end of life, death and bereavement.**

☐ Yes      ☐ No

**Name:**

**Address:**

**Email:**

**Telephone:**

**Mobile:**

## **Appendix 2 (ii): Questionnaire: Follow-up**

# **Research Questionnaire**

## **Talking about death, dying and loss**

We would be very grateful if you could take a few minutes to complete this short questionnaire. It is a follow-up to the questionnaire you completed around the time of the Living Well Dying Well Public Health Programme presentation at St Luke's Hospice. Some of the questions are very similar to those we asked before; this is done on purpose to see whether and how things have changed.

Your answers and those of other people are very important to us and will be used to see whether these sessions make any difference to the people who attend, and how. Please be honest in your responses, there is no need to be polite.

The completed questionnaires will be kept securely at the University of Liverpool and any information you give will be kept confidential.

It is up to you whether you complete the questionnaire or not, and you may also choose to leave out any questions that you do not want to answer.

**Miss Katharine Abba**  
**PhD student**

**Prof Mari Lloyd-Williams**  
**Supervisor**

Please write today's date here: \_\_\_\_\_

## A. ABOUT YOU

### 1. Are you considering making a will?

- ☐ Yes                      ☐ No                      ☐ I have already made a will
- ☐ I already have a will but am considering making changes to it

### 2. Have you ever talked with close family or friends about your wishes about your care if you became unwell and at the end of your life?

- ☐ Yes
- ☐ No

### 3. How comfortable would you feel about talking with a close family member or friend about your wishes about your care if you become unwell and at the end of your life, if you wanted to talk about it?

(circle one answer on a scale of 1 to 10)

1= Not at all comfortable  
comfortable

10= Completely

1      2      3      4      5      6      7      8      9      10

### 4. Have you ever talked with close family or friends about your wishes about what you would like to happen after your death?

- ☐ Yes
- ☐ No

### 5. How comfortable would you feel about talking with a close family member or friend about your wishes about what you would like to happen after your death, if you wanted to talk about it?

(circle one answer on a scale of 1 to 10)

1= Not at all comfortable  
comfortable

10= Completely

1      2      3      4      5      6      7      8      9      10



**6. Have you ever talked with close family or friends about their wishes about their care if they became unwell and at the end of their life?**

☐ Yes

☐ No

**7. How comfortable would you feel about talking with a close family member or friend about their wishes about their care if they become unwell and at the end of their life, if they wanted to talk about it?**

(circle one answer on a scale of 1 to 10)

1= Not at all comfortable  
comfortable

10= Completely

1      2      3      4      5      6      7      8      9      10

**8. Have you ever talked with close family or friends about their wishes about what they would like to happen after their death?**

☐ Yes

☐ No

**9. How comfortable would you feel about talking with a close family member or friend about their wishes about what they would like to happen after their death, if they wanted to talk about it?**

(circle one answer on a scale of 1 to 10)

1= Not at all comfortable  
comfortable

10= Completely

1      2      3      4      5      6      7      8      9      10

**10. Have you ever needed to comfort or support a friend or family member who has recently experienced the death of somebody close to them or is caring for somebody who is dying?**

☐ Yes

☐ No

**11. How comfortable would you feel talking with a family member or friend about the death of somebody close to them, if they wanted to talk about it?**

(circle one answer on a scale of 1 to 10)

1= Not at all comfortable  
comfortable

10= Completely

1      2      3      4      5      6      7      8      9      10

## **A. ABOUT THE LIVING WELL DYING WELL PRESENTATION AND 'HOW TO' WORKSHOP**

### **12. Which events did you attend?**

- ☐ An hour-long presentation by the 'Living Well Dying Well' team
- ☐ A two or three hour long 'How to' workshop
- ☐ Both a presentation and the workshop

### **13. Was anything at the presentation or the 'how to' workshop particularly relevant, useful or thought-provoking for you?**

- ☐ Yes
- ☐ No

If 'yes' what was it?

**14. Since the presentation or 'how to' workshop, have you talked with anybody close to you about your own end of life wishes?**

☐ Yes

☐ No

**If 'yes' do you think the attending the presentation or workshop encouraged you to do this?**

☐ Yes

☐ No, I would have done this anyway

**15. Since the presentation or workshop, have you done anything else or made any other changes in your life because of what you heard there?**

☐ Yes

☐ No

If 'yes' what were they?

**16. Do you have any other comments?**

Thank you very much for your help.

Please return the completed questionnaire using the enclosed pre-paid envelope to:

**Miss Katharine Abba  
Academic Palliative and Supportive Care Studies Group (APSCSG)  
Waterhouse Building  
Block B 1st Floor  
1-5 Brownlow Street  
Liverpool  
L69 3GL**

### **Appendix 3: Interview Topic Guide**

1. First could you tell me a little bit about yourself
  - a. Age, occupation, family, health, hobbies etc
  
2. How important do you think it is that people talk to their friends and family about their own end of life and death wishes, even if they are not ill at the moment?
  - a. Why? (any examples?)
  - b. What do you think might stop people talking openly?
  - c. What do you think might be done to help people to talk openly about their own end of life and death wishes, if this is what they want?
  
3. How good do you think people are generally at talking to and comforting others who are dying, or caring for somebody who is dying?
  - a. Why? (any examples)
  - b. What do you think stop people being as supportive to each other as they could be?
  - c. What do you think might help people to support one another at these difficult times?
  
4. How good do you think people are generally at talking to and comforting others who have been bereaved?
  - a. Why? (any examples)
  - b. What do you think stop people being as supportive to each other as they could be?
  - c. What do you think might help people to support one another at these difficult times?
  
5. Is there anything else that you would like to tell us about the subject of 'talking about death, dying and loss'?

## **Appendix 4: Participant Information Sheet**

### **Participant Information Sheet**

**Title of the Research Study:** Talking about death, dying and loss

#### **Invitation:**

You are invited to take part in a research study. You do not have to accept this invitation and should only take part if you wish to do so. Before you decide whether or not to participate, it is important that you understand why the research is being undertaken and what it will involve for you. Please take time to read the following information. Ask us if you would like more information or if there is anything that you do not understand. You may also wish to discuss this with your family or friends.

#### **What is the purpose of this study?**

It is often noticed that when the a person who is dying has previously discussed their death and end-of-life wishes with their family and friends, those involved often seem to experience less distress than they might otherwise have done. However, we know very little at the moment about how, why and when people talk to each other about death, dying and loss, how these conversations affect people's later experiences of dying and bereavement, and what might make it easier for people to have these conversations, if they would find them helpful.

The purpose of this study is to find out more about this by talking to people about their views and experiences of talking about death, dying and loss. If we can gather information about this it could help to inform the development of new ways of helping people to talk more openly among themselves about death, dying and loss, so that they can feel better prepared for their own death or a loved one's death when it comes. Katharine Abba is a researcher working with the Principal Investigator Professor Mari Lloyd-Williams at the University of Liverpool. Katharine will be working on the project for three years as part of a PhD.

This study is being funded by St. Luke's Hospice in Cheshire and has been reviewed by the University of Liverpool Research Ethics Committee.

#### **Why have I been chosen to take part?**

We are looking for a wide range of people to take part in the study, you do not need to have any particular experience or interest. We have chosen you because you attended a presentation by the Cheshire Living Well Dying Well Public Health Partnership and completed a form there giving us permission to contact you about this research.

**Do I have to take part?**

It is up to you to decide whether or not to take part. You can also decide to withdraw from this study at any time. You do not have to give a reason and you will not be affected in any way should you wish to withdraw. If you decide to withdraw, the project researcher will ask for permission to use the information collected from you to this point but you do not have to agree to this.

**What will happen to me if I do take part?**

If you decide to take part, please contact Katharine Abba by telephone on 0151 795 5314, or by email at [k.abba@liverpool.ac.uk](mailto:k.abba@liverpool.ac.uk). She will discuss the study with you in more detail and, if you still wish to take part, will make an appointment to come and see you at a time and place convenient for you. When she visits she will talk to you again about the study and ask you to sign a consent form. You will be given a copy of the consent form to keep.

Katharine will ask you about your views and experiences relating to talking about death, dying and loss, and invite you to talk as much as you like about these. She will record the conversation on a portable digital audio recorder, with your permission. This will mean she can concentrate fully on what you are telling her without having to take notes. The meeting will last about an hour but this depends upon you and what you want to tell her. If you do not meet Katharine in your own home, any travel costs or those associated with taking time from work to meet her will be refunded to you. We will need a receipt to do this.

**What are the benefits of taking part?**

If you decide to take part in this study you will help us to find out more about how people talk to one another about death, dying and loss. There are no direct benefits to you, although other research has suggested that talking about past experiences can sometimes be helpful.

**Are there any disadvantages to taking part?**

It is possible that during the meeting you may recall an upsetting time or event. If you become upset, if you wish, Katharine will stop the recording and discontinue the discussion. You may feel able to continue after a short break. If you prefer, the meeting can be arranged for another time or you may decide not to continue at all. If anything untoward happens to you, this study is covered by the University of Liverpool indemnity scheme.

**What if I am unhappy or there is a problem?**

If you are unhappy at all please contact Professor Lloyd-Williams, 0151 794 5605 or Katharine Abba, 0151 795 5314 and we will try to help resolve the problem. If you remain unhappy please contact the University Research Governance officer on 0151 794 8290 or email the ethics committee at [ethics@liverpool.ac.uk](mailto:ethics@liverpool.ac.uk). When contacting the Research Governance Officer please tell them the name of the researchers, what the study is called which is at the top of this page and the nature of your complaint.

**Will the information I give be kept confidential?**

The information that you tell us will be kept confidential. Katharine will make sure that the information is kept anonymous and safe at the University. The only people who will be able to see these are Professor Lloyd-Williams, Katharine Abba and another research supervisor, Dr Paula Byrne. If anything you say is quoted for publications in journals, presentation at conferences or similar, these will be anonymous and you will not be identified at all. Any personal details you give to enable us to send information and to contact you will also be confidential and kept securely.

**What will happen to the findings from this study?**

The findings will be published in international and national journals and may be presented at conferences and research meetings. This is so as many people as possible can hear about the findings and take action in the future. A summary of the findings will also be available to you if you wish. The findings will also form the basis of Katharine's PhD thesis for examination by the University of Liverpool.

**What will happen if I decide I do not want to continue taking part?**

If at any time you decide you do not want to carry on taking part in the study it is not a problem. Your participation is voluntary and your withdrawal will have no consequences for you whatsoever. You will need to contact Katharine Abba, 0151 795 5314 or Professor Lloyd-Williams, 0151 794 5605 to tell them you have changed your mind.

**Who do I contact if I have further questions?**

If you have any more questions about this study, please contact Katharine Abba, 0151 795 5314, [k.abba@liverpool.ac.uk](mailto:k.abba@liverpool.ac.uk), or Professor Lloyd-Williams, 0151 794 5605, [mlw@liverpool.ac.uk](mailto:mlw@liverpool.ac.uk).



## CONSENT FORM

### Title of Research Project: Talking about death, dying and loss

#### Researcher(s):

Professor Mari Lloyd Williams, Honorary Consultant in Palliative Medicine,  
Academic Palliative and supportive Care Studies Group, Department of Health  
Services Research. [mlw@liverpool.ac.uk](mailto:mlw@liverpool.ac.uk) Tel: 0151 794 5605  
Katharine Abba, PhD student. [k.abba@liverpool.ac.uk](mailto:k.abba@liverpool.ac.uk) Tel: 0151 795 5314

#### PLEASE INITIAL BOX

1. I have read and understood the participant information sheet version 2, dated October 2012 for this study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from this study at any time without giving a reason or my statutory rights being affected. ☐
3. I understand that under the Data Protection Act, I can ask at any time to access the information I provide. I can also request the destruction of this information if I wish. ☐
4. I understand that my interview will be audio recorded. I agree to this and to the use of any information I give being used in anonymous form in publications, conference presentations or similar events. ☐
5. I agree to take part in the above study. ☐

_____	_____	_____
Participant Name	Date	Signature
_____	_____	_____
Researcher Name	Date	Signature

## Appendix 6: Ethical Approval Letter

Dear Professor Lloyd-Williams

I am pleased to inform you that the Sub-Committee has approved your application for ethical approval for your study. Details and conditions of the approval can be found below.

**In order that this approval is valid, please ensure that you send a signed copy of the final version, with all supporting documentation, to the Research Governance Officer, Legal, Risk and Compliance, 2nd Floor Block C, Waterhouse Buildings, Liverpool, L69 3GL within 5 days of receipt of this email.**

Ref: RETH000583

Sub-Committee: Non-Invasive Procedures

PI: Professor Mari Lloyd-Williams

Title: What interventions can help encourage people to talk more openly with one another about issues relating to end of life and death, and what difference can they make to people's lives? (Short title: Talking about death, dying and loss)

First Reviewer: Prof Simon Frostick

Second Reviewer: n/a

Third Reviewer (if applicable): n/a

Date of initial review: 26/10/12

Date of Approval: 26/10/12

The application was APPROVED subject to the following conditions:

### Conditions

- |   |           |  |
|---|-----------|--|
| 1 | Mandatory | M: All serious adverse events must be reported to the Sub-Committee within 24 hours of their occurrence, via the Research Governance Officer ( <a href="mailto:ethics@liv.ac.uk">ethics@liv.ac.uk</a> ). |
|---|-----------|--|

This approval applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Sub-Committee should be notified. If it is proposed to make an amendment to the research, you should notify the Sub-Committee by following the Notice of Amendment procedure outlined at <http://www.liv.ac.uk/researchethics/amendment%20procedure%209-08.doc>. If the named PI / Supervisor leaves the employment of the University during the course of this approval, the approval will lapse. Therefore please contact the RGO at [ethics@liverpool.ac.uk](mailto:ethics@liverpool.ac.uk) in order to notify them of a change in PI / Supervisor.